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ABSTRACT

This manual is intended to assist individuals with disabilities or their families to protect their rights and solve their problems through developing appropriate advocacy skills. Chapter 1 defines advocacy, discusses different types of advocacy, and examines attitudes towards advocacy that may help or hinder its practice. Chapter 2 describes basic steps involved in solving most types of advocacy problems. In chapter 3, the importance of carefully analyzing and defining the problem situation before taking action is stressed. A guide for problem analysis and examples are provided. Chapter 4 focuses on the information gathering process. Chapter 5 discusses keeping records and includes sample forms. In chapter 6, the importance of developing a written plan of action is discussed, with examples. Chapter 7 considers the concept of assertiveness and provides guidelines for assertive verbal and nonverbal communication. Chapter 8 builds on these communication techniques by discussing negotiation and communications in meetings. Chapter 9 describes effective letter writing, and in chapter 10, the importance of following up is emphasized. The final chapter describes systems advocacy and lists sources of further information. The appendices include: a catalog of laws pertaining to the rights of persons with disabilities; a guide to understanding legal citations; a glossary of terms; a list of resource agencies and organizations; and a set of sample forms. (DB)

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Don't Get Mad Get Powerful!

A Manual for Building Advocacy Skills

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Don't Get Mad: Get Powerful!

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This manual is dedicated to persons who are differently able and to their families, in appreciation for all they have taught us.

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WHY LEARN ABOUT ADVOCACY?

Jan suspected her son, Jason, had a learning disability so she asked the school to test him. After the testing, the school called a meeting (an Individualized Educational Planning Committee (IEPC) meeting) to talk about the results. Jan has just returned from the meeting feeling confused and very frustrated. The only thing that Jan did understand about the tests was that they showed Jason had a learning disability. There were a lot of professionals at the meeting and Jan felt alone, anxious and afraid to ask questions. She signed a form saying Jason was eligible for special education services but Jan does not feel the services described in the plan are right for Jason.

Jan's next experience could be different. If she gains advocacy information and skills, she could be more effective in helping Jason get the services he needs.

Jim went to see a vocational rehabilitation counselor about getting job training. He was paralyzed in a car accident two years ago and just graduated from high school. The vocational rehabilitation counselor told Jim he was not eligible because he lives in a rural area and does not have his own transportation to get back and forth to a training program. Jim is very discouraged. He has no job and no skills. Is there something he can do? Yes. When Jim learns more about his rights and how to advocate, he will be more successful in getting the services he needs.

Have you ever felt that services you or your family receive are not right? Or felt that you have been treated unfairly? If you have, and you felt unsure of what to do or where to turn, this manual is for you.

The Purpose of This Manual

The purpose of this manual is to help you develop advocacy skills. We see advocacy as a special type of problem solving. Advocacy is problem solving to protect rights and to improve services. This includes many problem situations, like problems with: Social Security or welfare benefits, education, accessibility, housing, employment, residential placement, medical services, transportation, or protection from abuse or neglect. The advocacy examples in this manual concern rights of people with disabilities but the principles can be used to solve other problems too.

Professional advocates are available to help with problems, but the number of these professionals is small and as a result, they are not always available where needed. Yet when you or a family member has a disability, problems are plentiful and sometimes the same problem recurs year after year. If you learn to advocate, you will not be dependent on someone else to solve problems. You will gain more control over your life by developing advocacy skills.

Increased confidence will come with increased control over your life. You will learn that you have the power to achieve your objectives. It is ironic that many of us endure problems because we think we do not have the power to change things. As long as we believe we are powerless, we are powerless. When we begin to act as if we know what our rights are and to assert those rights, we will be perceived as powerful and treated with respect.

There are many types of advocacy: individual advocacy, systems advocacy, legal advocacy, and legislative advocacy. Here we will focus on individual advocacy. By this we mean advocacy skills you can use for yourself or for other individuals, like your children, friends, neighbors or people you work with on a professional basis. Although our focus is on individual advocacy, there are times when many persons experience the same problem repeatedly as a result of an agency policy, a law, or lack of needed programs or services. In these cases, it makes sense for people to work together to change the system of service delivery. This is called systems advocacy and is discussed briefly in Chapter 11.

Outline of the Manual

Advocacy involves skills and processes that anyone can learn. We hope to help you learn these. This manual includes the following topics selected to start you on your way to mastering the art of advocacy. Chapter one defines advocacy, discusses different types of advocacy, and examines attitudes towards advocacy that may help or hinder your practice of advocacy. Chapter two describes basic steps involved in solving most types of advocacy problems. An understanding of these steps will give you a basic framework for approaching advocacy. In chapter three, we explain the importance of carefully analyzing and defining the problem situation before taking action. We include a guide for problem analysis and provide examples.

Information gathering, critical to successful advocacy, is covered in chapter four. Information is most useful when organized and recorded in a way that allows you to find and use it when needed. Chapter five discusses keeping records and contains sample forms. In chapter six, we discuss the importance of developing a written plan of action and show examples of advocacy plans.

Implementing an advocacy plan requires assertive communication. Chapter seven discusses the concept of assertiveness and provides guidelines for assertive verbal and nonverbal communication. Chapter eight builds on communication techniques discussed in the previous chapter by discussing negotiation and communications in meetings. Chapter nine describes effective letter writing. In Chapter ten we highlight the importance of follow-up. The final chapter describes systems advocacy and provides brief guidelines and sources of further information.

The Appendices contain information you will find useful in your advocacy efforts. Included are: a catalog of laws pertaining to the rights of persons with disabilities; a guide to understanding legal citations; a glossary of terms; a list of resource agencies and organizations; and a set of blank forms you can use to plan and implement your advocacy efforts.

CHAPTER I

UNDERSTANDING ADVOCACY

Advocacy Defined

There are several definitions of advocacy. If you look it up in a dictionary you will find ideas like:

- pleading the cause of another;
- defining rights and interests of another;
- espousing a cause by argument;
- supporting or upholding.[1]

These ideas about advocacy are accurate. We certainly are not going to argue with Webster. But these ideas make advocacy sound out of the reach of an ordinary person. Advocacy is not mysterious or out of your reach.

---

[1] Webster's New Twentieth Century Dictionary of the English Language, 2nd edition, S.V. "Advocacy."

In a practical sense, advocacy is a type of problem solving. Problem solving is something we all do quite often. It is finding the best way to improve a situation we are not pleased with. We would not call all problem solving advocacy. Advocacy is problem solving used:

1. To protect rights or change unfair discriminatory or abusive treatment to fair, equal and humane treatment.

2. To improve services, gain eligibility for services or change the amount or quality of services to better meet the needs of an individual.

Types of Advocacy

There are many different types of advocacy and we are going to briefly describe these now to give you a good idea of how what you will be learning fits into a range of advocacy activities.

Professional vs. Lay Advocacy

Some people work as professional advocates for pay. Professional advocates may be self-employed or employed by an agency. In this manual, we will be talking about lay advocacy which is advocacy on a volunteer basis. Lay advocates use advocacy from time to time to solve problems for themselves or family or friends. Lay advocates may also work as community volunteers for specific groups like the Association for Retarded Citizens, Michigan Society for Autistic Citizens, Association for Children and Adults with Learning Disabilities, the Epilepsy Foundation, or the United Cerebral Palsy Association.

Internal vs. External Advocacy

Internal advocates are usually professional advocates employed by an agency to protect rights and handle complaints of citizens served by the agency. For example, vocational rehabilitation agencies employ advocates to help vocational rehabilitation clients with complaints against the agency. The Michigan Department of Mental Health has an Office of Recipient Rights (ORR) and so do community mental health agencies. These offices help recipients of mental health services who experience a rights problem. Internal advocates can help cut red tape and solve problems, but at times face a conflict between the interests of the client and the interests of the agency for which they work.

Individuals working for an agency can act as informal advocates within the system. Such individuals do not work as advocates officially, but when decisions are made they speak up on behalf of client interests.

External advocates are usually professional advocates employed by an agency or organization that deals only with advocacy and related issues. The agency or group has no formal ties to service providers. External advocates seldom find themselves in a conflict between the interests of a client and the interests of their employer. Michigan Protection and Advocacy Service is an example of an external advocacy agency. It helps persons with developmental disabilities solve advocacy problems but it is not part of any agency that provides services. It is run by an independent board of directors.

Individual vs. Systems Advocacy

Individual advocacy is working on behalf of a single individual. This could be on one's own behalf, on behalf of a family member, friend or client. This usually involves changing the decision of a caseworker or changing the behavior of a direct service provider. Systems advocacy is working to change policies, rules or laws in order to benefit many people. Systems advocacy can be done by individuals, groups, organizations or coalitions.

This manual focuses on helping a lay advocate, external to a service system, gain knowledge and skills needed to solve problems of an individual.

The Importance of Attitudes

Your attitudes about advocacy are critical to your success. As a society we hold many different cultural values. Some of these values make it hard to feel good about yourself when you advocate; but others can make you feel good about your advocacy efforts. A good understanding of the values which shape attitudes about advocacy will help you create a positive image of yourself as an advocate.

Most of us are brought up to be nice, agreeable and cooperative. We are taught it is bad to disagree, to confront and to feel angry. Women have been especially discouraged from being assertive or thinking of themselves as powerful. All of us are discouraged from "rocking the boat." Advocacy requires some "boat rocking." It involves identifying problems and calling for solutions. It often entails disagreements, confrontation and constructive use of anger. When advocating, these qualities leave us wide open for rejection and criticism, for being labelled as a complainer or troublemaker. At times we may fear others will retaliate or get back at us if we are uncooperative.

It is possible that you will be labelled as a "complainer" or a "troublemaker" in an advocacy situation. It would be easy to say, do not let this bother you. If you always try to please others and be agreeable, this advice will not help you much. Thinking carefully about the questions below may help you put a fear of criticism into perspective, and that is what you must do. An advocate does risk criticism, and while it is natural to feel anxiety about criticism, it is essential to keep any anxiety in perspective.

Questions about criticism

1. Do you believe that people should have the right to give opinions, to disagree and to try to change conditions? If you believe people in general have these rights, do you really believe you have these rights? If you

believe people in general have these rights but you do not, why is this so?

2. Do you believe in the things for which you will advocate? Do you care about the people for whom you will advocate?

3. In the situations you may face, who might not like your advocacy? How many people are involved? How important is it to please these people? How hard do these people try to please you?

4. Are there people or other resources that can help you take risks?

Our society also places a very high value on individual rights and freedom. Laws that protect the rights of individuals with handicaps reflect the high value we place on individual rights. The federal Rehabilitation Act of 1973 (as amended) requires an individualized rehabilitation plan for each vocational rehabilitation client. Persons with developmental disabilities receiving services from the Michigan Department of Mental Health or a community mental health agency must have an individualized program plan. Each of these plans, by law, must describe the needs of the individual and the services which will be provided to meet those needs.

Although several federal and state laws say that services must be individualized, there is often a need for advocacy because agencies develop budgets and plan programs in terms of groups of clients, not individuals. Agencies submit budgets and operating plans several years in advance. These budgets and plans are based on projections about groups of clients to be served. Teachers, caseworkers, buildings, buses, materials, supplies and related services personnel are all assigned in terms of programs and geographical locations. To complicate matters, laws describe long lists of services which can be provided but there is not enough money to provide all services to all clients. The most common problem in individual advocacy is to get an agency or school to effectively individualize services to meet your needs. The attitude you must keep in mind is that you have a right to individualized services. The fact that you probably will have to advocate to make this happen should not be taken personally -- this is a result of problems in the service system.

A final attitude dilemma has to do with professionalism. Most service providers you meet are professionals with academic degrees and experience. You certainly want to benefit from this knowledge and experience. However, it is false to believe that professionals know everything and lay persons know nothing. Federal and state laws require agencies to get input from the people they serve in developing agency plans and service plans for individuals. This means that legislators and members of Congress believe the input of nonprofessionals is important. You have the right to ask questions, give information, ideas and opinions, and to disagree. Do not let professional titles, degrees, technical words, and jargon make you feel anxious about contributing your ideas.

Summary

In this chapter, we defined advocacy as a problem solving process used to protect rights and improve services. We also discussed types of advocacy, and most importantly, attitudes that are essential for success as an advocate.

Follow-up Exercise

Calling On Your Previous Experience

Most of us have advocated for ourselves or for others at some time in our lives. Recalling and thinking about these experiences can help you in several ways:

1. You can become more comfortable with the idea of advocacy by realizing you already have some experience.

2. You can increase your motivation to learn more about advocacy by recognizing there are many ways to use advocacy skills.

3. You can begin to identify your problem solving strengths and weaknesses and decide which to concentrate your efforts on.

To identify your previous advocacy experience think carefully about the following questions and answer them as thoroughly as possible.

1. Think of at least two situations in which you advocated for yourself. Here are some typical situations that involve self-advocacy:

   * unfair school test score;
   * repairs to your car were not satisfactory;
   * denial of a health insurance claim;
   * unequal treatment on the job;
   * errors in credit card billing;
   * landlord-tenant problems (making repairs, return of security deposit);
   * unequal sharing of household tasks.

2. Pick one of your self-advocacy experiences and recall it in as much detail as possible.

3. How did you feel about the outcome of your self-advocacy efforts? Are there reasons for your feelings? What are they?

4. Can you recall all the steps you went through in deciding what to do and in carrying through with your plans? How did you feel during this process? Did you want more information, assistance or resources during that process? Did you feel in control of the process? What worked and what did not work? If you had the

chance, what would you change? Did the process take a long time? Could the same end have been accomplished in less time or with less stress on you?

5. What strengths do you bring to the advocacy process? What areas do you want to work on in order to improve your advocacy skills?

CHAPTER II

AN OVERVIEW OF STEPS IN THE ADVOCACY PROCESS

Steps In the Advocacy Process

Although each advocacy problem is unique, the process of advocating can be broken down into a set of basic steps, which form a framework you can use in approaching any advocacy situation. These are basic problem solving stages and, as such, will give logic and direction to your efforts. The steps are:

Problem definition

Information gathering

Action planning

Assertive action and

Follow-up

Problem Definition

Advocacy takes time and effort. Developing a clear and specific definition of the problem helps minimize waste of these precious resources. Defining the problem means sifting through your experience of the problem situation to separate facts from feelings and to distinguish major issues from details. It means getting to the heart of the issue and, if possible, figuring out what is causing it. In some cases, defining the problem also leads to ideas for solution.

Complex situations may actually involve several different problems. If so, it is important to define each since they may require very different strategies. If you are dealing with more than a single problem, we also suggest that you prioritize and work on the most important one first. The next chapter contains more information on problem definition and includes a guide to help you in this stage of advocacy.

Information Gathering

Once you have a clear picture of the problem, you need to begin gathering information that you will use in planning and carrying out your advocacy. The type of problem will determine the type of information you will need. For most types of problems you will definitely want to know whether laws or written policies apply and whether there are procedures for resolving or appealing disagreements. As you gather information, you will also analyze it in terms of your situation and possible solutions.

Action Planning

During the action planning phase, you will thoroughly analyze the information you have gathered in terms of your problem and the solution you desire. Following this analysis, you will develop one or several alternative, step-by-step plans for what you will do to resolve the problem. The more detailed your plan, the better prepared you will be when you begin the next phase. The plan should include activities of others who may be helping you, potential responses to your advocacy efforts and ideas for how you will deal with responses. A good plan should also include a schedule. A schedule can provide motivation for you to continue working until the problem is solved. It also places some limits on how long you are willing to wait for an active response to your efforts.

Assertive Action

In the assertive action stage, you carry out the plan you have worked so hard to research and develop. Your action stage may involve one or a very few steps, like writing a letter of complaint, or it may involve a whole series of events and involve many people. An important element of success is the use of good communication skills. These skills include an assertive attitude, active listening, appropriate nonverbal behaviors, the use of well chosen advocacy communication techniques and negotiation strategies.

Follow-up

It's likely that your advocacy plan will result in a verbal agreement that the change you are working for will be made. However, you must follow up to ensure that all agreements reached are carried out and that promises made are promises kept. This involves clarifying when changes should be expected and who will be responsible for them. It also involves checking to see if agreements are actually implemented.

In many situations one or more of the advocacy phases described above must be repeated during the advocacy process. For example, you may decide you need more information after you have begun your action planning. In some cases you may decide to redefine the problem midway through the advocacy process. Don't be discouraged if this happens. It's better to take time to rethink your plan than to stick with a plan that isn't working. Good advocates are flexible and willing to try several approaches. They are also willing to continue their efforts until the problem is solved.

CHAPTER III

PROBLEM DEFINITION

Problem definition is the first step in the advocacy process. The vague feeling that something is wrong can motivate you to change matters but it does not give you much direction. To define the problem you will work with what you feel and know about the problem to give it a concrete, specific definition.

Here are some examples of problems stated first in general, vague terms and then restated in specific, concrete terms.

Example 1:

Vague: Jeff's special education program is not working.

Specific: The only special education service that Jeff receives is two hours a day in a resource room which serves students with mild mental retardation, students with learning disabilities, and students with emotional problems. The teacher is not experienced in the newest methods for teaching students with learning disabilities like Jeff and does not have time to individualize instruction. Jeff needs individualized reading instruction which requires him to use all his senses in learning.

Example 2:

Vague: Susan has a seizure disorder and works as a secretary. Her employer is discriminating against her.

Specific: All other secretaries received training on a new word processor. Susan was not given the opportunity to take the training and she wants the chance to learn this new skill.

Example 3:

Vague: Larry's guardian is not doing a good job.

Specific: Larry's guardian lives over a hundred miles away and sees Larry only once a year. The guardian does not know Larry's strengths, weaknesses or

> needs and does not attend meetings to review Larry's individualized program plan (IPP). Larry needs a guardian who will take time to get to know him and play an active role in ensuring his individualized program plan will meet his needs.

In the examples above the vague and specific statements are different. Can you describe how they are different? The vague statements describe judgments or conclusions. They use words like "not working," "unfair" or "not doing a good job." A specific problem definition includes behavior, events and circumstances that may lead to a conclusion or judgment that something is wrong. But statements that describe behaviors are objective. They are different from our feelings about them or the conclusions we draw. The specific statement also describes what is needed or desired in specific terms. Here again, the statement of need is an objective statement and does not include any reference to blame. Separating the objective facts of a situation from your feelings about it is important. The most effective problem solvers recognize their feelings about a situation but distinguish between the feelings and the facts.

How do you go from a vague statement to a specific one? One way to do this is to ask yourself a series of questions about the problem. The questions below can be used to identify specific, concrete details of a problem situation. It is a good idea to write out the answers to these questions. Writing your thoughts down often helps to clarify a problem. In addition, your written answers will be useful in later advocacy steps. If you do not like to write, talk the problem over with a friend or family member using the questions below as a guide. Ask your friend to take notes as you talk to help you get a clear picture of the problem.

Problem Definition Questions

1. How do you know there is a problem?

2. How do you feel about the problem?

3. Who is affected by the problem? Make sure to list all persons affected by the problem.

4. How is each person you listed in your answer to the question above affected by the problem? Be specific. List concrete ways in which the problem affects each person.

5. When did the problem start? Has it been a continuous problem? Is it worse at certain times?

6. What started the problem, made it worse or caused you to notice the problem?

7. What kinds of changes would solve the problem? Try to think of several alternatives.

8. How will you know when the problem is solved?

9. What has been done to address the problem so far? What happened as a result of this? Should this be continued or does something else need to be tried? What?

10. By what date should the problem begin to be resolved? How long should this process take?

11. If the problem is not solved, how will that affect each of the persons involved?

Below is an example of using problem defining questions to go from a vague to a specific statement.

Situation:

Jean's son, David, has moderate mental retardation and a seizure disorder. He is 21 years old and lives in a group home. Last Sunday Jean brought David over to her home for the day. David seemed to have regressed in his decision-making skills and he looked sloppy.

1. How do you know there is a problem?

It was hard for Jean to be specific, but here is the list of problem signs that she finally came up with:

a. David's shirt was wrinkled and looked as if it had not been hung up or ironed.

b. David's teeth looked yellowed and his gums were very puffy.

c. David's hair had just been cut in an extremely short, unflattering brush cut. When asked if he liked his new haircut, David said he did not know. He did not seem to recognize he had a right to choose a style.

d. When asked what he did in the evening, he said he watched television like he was supposed to.

2. How do you feel about the problem?

Jean felt worried because she loves her son. She also felt angry because she believes David is not getting proper supervision in personal care skills and is not being encouraged to choose his own leisure activities.

3. Who is affected by the problem?

David and Jean are affected, and other residents of the group may also be affected.

4. How is each person affected by the problem?

David:

> His appearance is poor. This seems to reduce his self-confidence. This also affects how others react to him. When Jean and David went out to eat, Jean noticed more stares and funny looks. David's health may be affected. His puffy gums could be a sign of gum disease. Treatment for this is expensive and uncomfortable; sometimes painful.

David is not making choices about what to do in his spare time. Without practice and encouragement, he will lose skill in making decisions. He seems depressed and is losing interest in learning.

Jean:

Jean is not concentrating well at work because she is worried. She has been getting into arguments with her husband over silly little things.

Other residents:

Jean does not know how other residents are affected yet. She could get an idea by visiting the home and spending some time there in the evenings or on weekends. Possibly she could find a way to meet relatives of the other residents and talk to them.

5. When did the problem start?

This is the first time Jean noticed the problem. She has not spent much time with David for the last two months since she went back to work. She has talked to him on the telephone, but has not actually been to the home or spent time with David.

6. What started the problem, made it worse or caused you to notice it?

Jean does not know what started the problem. She did not recognize any of the staff at the home when she picked up David. Jean noticed the problem by spending time with David. The change is very noticeable to her because she knows David so well.

7. What kinds of changes would solve the problem?

   a. David needs to be reminded to brush and floss his teeth regularly. Staff must monitor and reinforce his efforts since he has always disliked cleaning his teeth. He also needs to see a dentist.

b. David needs to have staff to work with him on making decisions about his appearance and how he spends his free time.

c. Perhaps different staff are needed.

d. Staff may need training.

e. Perhaps more staff are needed.

f. Staff may need better supervision.

g. It is possible that David should be moved to a different home.

8. How will you know when the problem is solved?

Jean believes the following signs would indicate the problem has been solved:

David would say he chose his own haircut.
David's teeth would look better.
David's clothes would look like they had been properly cleaned and hung up.

When asked what he does with his free time, David would describe at least one activity other than watching television.

David would say he was choosing activities that he likes.

9. What has been done to address the problem so far?

Jean has recognized the problem and decided to do whatever she can to solve it.

10. By what date should the problem begin to be resolved?

Jean feels the problem should be taken care of immediately.

11. If the problem is not resolved, how will it affect each person involved?

David:

His health will suffer. He may get gum disease and lose his teeth. He will lose decision-making skills. He could lose his interest in learning and may develop problem behaviors.

Jean:

Jean will get more worried and angry. She cannot imagine watching her son regress indefinitely.

Other residents:

The affect on other residents is unknown but they may be affected in ways similar to David.

As you work on problem definition, you may find you actually have several problems as in the example above. If this happens, decide which problem is most important and must be resolved first. Concentrate on this problem. Sometimes several problems can be resolved together. Later, when you take action, you will be negotiating with service providers. Some compromises may be necessary. If compromises are necessary, make sure you understand and can accept the compromise solutions without jeopardizing your main objective.

Summary:

The first step in advocating is to define the problem. This step is critical in finding ways to solve the problem. A good definition includes needs, behaviors, events and circumstances, not judgments. It is specific and concrete. If you are having trouble defining the problem, call a professional advocate for assistance.

CHAPTER IV

INFORMATION GATHERING

Information gathering is the second step of a five-step advocacy process. After defining the problem, you will look for information needed to plan your action. Although the kind of information you need will be different for different types of problems, there are important things to find out no matter what the problem.

Responsible Agencies

First, you want to find out who or what agency is responsible for the service or change you want. In some cases this will be obvious but in others this will take some research. Sometimes the primary advocacy problem is to establish that a particular agency does have responsibility for the service you desire. This may arise when several agencies have overlapping responsibilities and each keeps referring the situation to the other while the client remains unserved. It may also arise when no existing agency has responsibility.

There are several ways to gather information on responsible agencies. A good information and referral specialist can give the names and telephone numbers of agencies which provide services you need and can sometimes give you the name of a specific staff person within the agency to ask for when you call. Most medium-sized and large cities have agencies that specialize in information and referral. Michigan Protection and Advocacy Service provides information and referral regarding services for persons with disabilities.

Appendix C, Government Agencies and Departments in Michigan, also contains useful information on agency responsibilities. When your situation involves resolving disagreements about the responsibility of a particular agency, you may have to consult the law, contract or other specific document that created the agency. Such documents describe mandated responsibilities. It is easiest to find this information for programs that are created by law and funded by the government directly or through a contract.

Rights and Rights Procedure

All government agencies and most private agencies which provide human services guarantee certain rights to their clients. These rights are usually described in a brochure or handbook and are explained to the client (parent or guardian) at application for service. These rights vary from agency to agency but almost always include:

- the right to file an application and to have an evaluation of eligibility;
- the right to appeal eligibility and service decisions to an impartial authority;
- the right to have a say in service decisions;
- the right to confidentiality;
- the right to freedom from discrimination.

All government agencies have written procedures for complaints and appeals. You should get a copy of client (or parent) rights brochures and complaints and appeals procedures if you do not have these materials. You can get these materials by asking your service provider for them. If you have problems getting these materials, contact a professional advocacy agency like Michigan Protection and Advocacy Service.

Once you have these materials, carefully review the rights statement. Does this statement of rights help in thinking of ways to support your point of view? Write down your ideas and add a note that identifies where you got the ideas.

Secondly, study the complaint and appeals procedures to make sure that you thoroughly understand them. Mark any words or procedures you do not understand and call your service representative or an advocate for an explanation. You may never have to use these formal complaint and appeal procedures, since most problems are solved through informal procedures like meetings, telephone calls or letters. Nevertheless, it is important to understand all of your options, since the more you know, the more effective and confident you will be.

Agency Chain of Command

In addition to knowing which agency is responsible, knowing the chain of command for the agency gives you a valuable negotiating perspective and may be a source of leverage later. For example, the local school district is responsible for providing special education services to all eligible students within the district. Local districts are grouped together at the county level in a unit called the intermediate school district (ISD). Some specialized services can be provided by the ISD. Furthermore, the ISD has responsibility for planning and monitoring services throughout the ISD and for investigating complaints. Finally, ultimate responsibility for special education services rests with the state. The Special Education Service Area of the Michigan Department of Education reviews and approves ISD plans, and distributes (and may withhold) state and federal money for special education. This unit is also responsible for part of the hearings and complaints process.

Most major services have more than one administrative level -- there are usually local, county and state administrators. If you are not satisfied with what you are told by a local administrator, it is definitely worthwhile to go to a higher level. Because county, state, or federal administrators may have a broader perspective and broader authority, you can often get good results by moving up the hierarchy. Furthermore, you have more bargaining power if local program representatives realize you are serious about resolving the problem and are knowledgeable about further action you can take.

Legal Basis

You can give more power to your arguments if you know about any laws which apply to your situation. The types of laws most likely to apply to your situation are: laws which guarantee rights, laws which describe standards agencies must meet in order to receive funds or laws describing licensing standards. Appendix A is an outline of the most important laws in the disability rights area. For most laws there is a companion set of administrative rules or regulations. Administrative rules and regulations describe how laws are to be implemented and thus they contain more information on what agencies must do. State laws are implemented by rules and federal laws are implemented by regulations. Rules and regulations have the force of law -- this means they must be followed. Not complying with rules and regulations is illegal. An advocate should research not only the law but also, perhaps more importantly, the rules or regulations.

Appendix A includes citations for important laws and their implementing rules and regulations. Appendix B describes how to use the citations to find the documents you are interested in. You should be able to find your material in any large library containing law books. The Michigan

Protection and Advocacy Service has a reading room in its Lansing office. This reading room may be used to research advocacy problems in the disability rights area.

Once you have located a law which may cover your situation, review it and the rules or regulations to see if it does, in fact, apply to your situation. You may reach one of three possible conclusions:

1. The law specifically requires the kind of change you want. If the change is not made, the responsible party is out of compliance with the law.

2. The law says the responsible agency may make the kind of change you desire. Some laws list services which may be provided but not which ones must be provided to a specific person.

3. There may be no law which applies to your situation.

When you have found out whether any laws apply to your situation you should make a copy of the sections that apply. If there is a law that requires the kind of change you want, your next task is to gather any evidence or information that may be needed to show that the law applies to your situation.

If the law says the change you want could be made, but does not require it, you will need to gather more information about why the change is needed. This situation is very common since a number of major laws governing services to persons with handicaps describe a wide variety of services which may be provided. Such laws do not intend every person to receive every service. The laws require that an individualized service plan be developed for each service recipient. The individualized plan describes the individual's service needs and which specific services will be provided to meet those needs. The advocate's task is to show that a service is necessary for the recipient. For example, federal and state special education laws say that "related services" may be provided to students who are eligible for special education. Related services are defined in the federal special education regulations as follows:

> (a) As used in this part, the term "related services" means transportation and such developmental, corrective, and other supportive services as are required to assist a handicapped child to benefit from special education, and includes speech pathology and audiology, psychological services, physical and occupational therapy, recreation, early

> identification and assessment of disabilities in children, counseling services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training.
>
> 34 CFR 300.14

Not all students receive all related services. If a student needs speech therapy but is not receiving it, the student's advocate needs to describe why the student needs speech therapy in order to benefit educationally. Written recommendations from professionals are the most persuasive way to show that a need for a service exists. Other types of evidence could include detailed behavioral logs or diaries, testimony of others in similar situations, and textbook recommendations.

Where no law applies, the advocate must discover a way to show the change is needed and that a particular agency should take responsibility for making the desired change.

Information gathering includes thinking of logical arguments for why a change is needed. Once you have developed a logical reason it is easier to think of types of information you will need to make your point. To trigger your thinking, look over the list of potential reasons for change below.

Reasons for Change

1. The situation is inhumane or abusive.

2. The situation violates basic constitutional rights like freedom of speech, movement, privacy and so on.

3. The situation is discriminatory. Situations may be unintentionally discriminatory, meaning that although no one is intentionally excluding persons with handicaps, the effect of the situation is still discriminatory. For example, the effect of not providing an interpreter at a public meeting is discrimination against deaf persons. Unintentional discrimination is still discrimination.

4. The situation results in unnecessary segregation of handicapped persons.

5. The situation may endanger safety or health, immediately or in the long run.

6. The situation will result in loss of function or ability.

7. The situation violates standards of good practice or professional ethics.

Individual Files

When the problem involves services that an individual receives from a specific agency it is often important to review the individual's case file.

The case file of an individual is confidential and laws prevent information from being released, viewed, copied or discussed without the individual's written permission. The parent of a minor or a legal guardian has the right to access the files of his/her child or ward. Most agencies have a form to be used for getting written permission. The Family Educational Rights and Privacy Act (20 USC 1232g and 34 CFR 99.1 et seq) guarantees parents or legal guardians the right to look at and receive copies of their children's educational records. Laws authorizing the existence of other service agencies usually contain a section describing rights to look at your own file or the file of your minor child or legal ward. Agencies are often very reluctant to allow persons to look at their own files. You will almost always have to describe or cite the law that guarantees your right to review a file.

Files may contain a lot of information -- not all of it relevant. As an advocate, you will usually want to review the following parts of a case file:

1. The individualized service plan.

2. Tests or evaluations which describe the handicap and often contain recommendations.

3. Progress records.

Policy Documents

Another area to explore is the content of casework manuals or policy documents. Casework manuals are written by agencies for their case managers and other staff and they describe procedures that must be followed in providing services. Policies do not have the force of law, but they carry a lot of weight. Reviewing policy and procedures can give you insight into how staff of an agency look at a situation and also give insight into constraints on direct service providers.

Policies are public documents and you can get permission to read them by citing the Freedom of Information Act. Usually you will have to go to the agency office to review a manual. It is also important to describe the policy (or at least the subject matter) you want to review. You should request permission to review a casework manual or policy in writing. Make sure to date the letter and to keep a copy since verbal requests can be forgotten or lost. You are likely to get a favorable response to a short, clear letter of request. A sample letter requesting permission to review a case file and specific policy items is included in chapter nine on written communications.

CHAPTER V

KEEPING RECORDS

Keeping good records is critical to successful advocacy and to ensuring a high quality of service in general. When you argue for a change, detailed information on the situation will be useful and necessary to back up your argument. In the previous chapter, we discussed the information gathering phase of advocacy. This information is only useful if it is recorded in a way that allows you to find it and use it when you need it. Furthermore, to ensure a continuous level of high quality serivce, you must actively participate in program planning and good record keeping is the basis for your participation. To be effective, record keeping must be done on a continuous basis, not just when you are working on an advocacy problem. If you have not been keeping detailed records, now is the time to start.

Contents of a Record

There are many types of information that should be kept in a record. You should keep a record of all evaluations, tests and assessments including: the date, the name, address and phone number of the person who did the evaluation and a copy of the evaluation report or a summary of the report. It is also important to write down the highlights of all conversations you have with the evaluator.

Secondly, it is important to record all hospitalizations, surgeries, and treatments including medication types, schedules and dosages. These records should include dates, reasons for the service and the name of the treating physician or health professional.

Educational information is a third important type of information to record including: educational assessments, individual educational plans, progress reports and notes, a record of schools attended, copies of parent rights booklets, records of conversations and copies of letters exchanged between yourself and the school.

You should keep records on all services provided in relationship to the disability. This would include details such as dates, locations, type of service, who the provider is and how to contact the provider, as well as any individualized service plans and statements describing rights of service recipients.

Finally, it is important to record all expenditures you make related to the disability.

Creating a Record

The section above describes a tremendous amount of information that should be kept as part of a record. It is not hard to create a record however. Much of the information you will receive automatically such as: copies of individualized service plans, rights booklets, receipts for purchases, correspondence from schools, letters of eligibility for services and letters of closure or service completion. The challenge is to organize and store the information so it is available when you need it.

Each person will develop his or her own way of record keeping. Two basic methods are use of a looseleaf notebook or use of individual file folders.

Looseleaf notebooks

A looseleaf notebook with sectional dividers works well for many people. Major topic sections could include medical, education, vocational, expenditures, and rights. As your records accumulate, you may want to start a separate notebook for each topic area with sections for sub-topics such as tests and assessments, individualized plans, rights, progress notes, correspondence, records of conversations, etc.

File folders

If you have or can get a file cabinet, a set of file folders could be used to organize your records. Folders should be set up and labelled for the topic areas mentioned above.

The part of record keeping you will have to put the most effort into is creating a record of important meetings and conversations you have with service providers. The notes should include: the date of the conversation or meeting, the name and title of the person(s) you talked with, an address and telephone number for use in future contacts, the reason for the discussion, a summary of the main points discussed and a description of any agreement(s) or conclusion(s) reached. It's also important to list any follow-up needed as a result of the discussion. On the next page is a sample format for recording discussions. We encourage you to make copies of it for your use in recording meetings and conversations or to use it as a starting point for creating your own form.

ADVOCACY NOTEBOOK

Discussion Notes

DATE:________________ TIME:____________________

Kind of Discussion (telephone, meeting, other):__________

Discussion with:

Name:

Title:

Agency:

Address:

Telephone:

Reason for discussion:______________________________

____

Summary:_______________________________________

____

____

____

____

Agreements/Conclusions:____________________________

____

____

Follow up needed:________________________________

____

____

____

CHAPTER VI

THE ADVOCACY PLAN

After you have defined the problem and gathered basic information, we recommend that you develop an advocacy plan. Although it is not essential, we also recommend that the plan you develop be a written one. We have included an advocacy planning form in this Chapter and two examples of how the form was used by others. Using the form to write down your plan, will help ensure that you have considered all important aspects of your plan and have made the decisions necessary to begin your action.

There is nothing magical about the plan -- it is simply a problem solving tool -- but a very helpful one since you can use it as a roadmap to guide you through the rest of the advocacy process. In developing the plan you will describe your starting point, your destination, and what you will do to reach your destination. The plan will also include a tentative schedule giving you an idea of when you can expect to reach your goal.

Elements of the Plan

To start your advocacy plan, write out a short statement of the problem. Although this may seem repetitious if you have followed the problem definition recommendations in chapter 4, writing a statement of the problem in your plan will help you to focus your thinking and it will be a helpful reminder if you get stuck or side tracked.

Next, decide what you would like to achieve as the ideal solution to your problem and write it down. One of the greatest barriers to successful advocacy is being unclear about what you are trying to accomplish. If you are unsure of your goal, talk to friends, relatives, professional advocates and service providers to get ideas.

Although it is critical to decide on an ideal solution, it is important to realize you may not reach this goal. It may be necessary to make some compromises. In other words, you may not get everything you ask for. To prepare yourself for this possibility, try to see the outcome of your efforts as a continuum ranging from getting everything you want, various combinations of some of what you want, and including the possibility of getting nothing. Decide on some compromise solutions that are acceptable although not ideal. Later, if a compromise is reached, you will still achieve an acceptable solution and the other party will probably feel that they have accomplished something by causing you to accept less than you had originally asked for. You probably will also be perceived more favorably if you show a willingness to work out a solution with the other party than if you insist on only one outcome.

The next step in developing your advocacy plan is to list all of the information you need to reach your desired outcome. Divide this list into two sections--one labelled "Information I already have" and the other labelled "Information I need to obtain". Review the notes you took and material you collected during the information gathering stage. List laws, rules, regulations, and policies that support your point of view and write down references or citations. In addition, list ethical, moral, humanitarian, logical and political reasons for your desired changes. List any facts that need to be established (e.g. that a handicap does exist). Add to your list any information that will help show that the change you desire is needed.

Try to put yourself in the other party's place and attempt to discover how the changes you want could benefit them also. Think of as many reasons as you possibly can and then look back at your list, and decide which are most likely to be effective in influencing the other party. Mark the most effective arguments and plan to use these first but save the others for possible use later. Note down all types of information you still need to gather and allow opportunities to gather this information when you develop your plan.

Next, think about the other party. What are their needs, their priorities? What arguments do you expect them to make? Write down these arguments on your plan and then think about what you will say or do in response to these arguments. Write down ideas on how you will respond.

Next, write down a step-by-step plan for how you will approach the other party and argue your point of view. This could involve a sequence of telephone calls, a letter and one or more informal meetings, with a follow-up letter summarizing agreements reached. The method you select will depend on your situation. You will want to identify the name, telephone number and mailing address of the person you will be dealing with and perhaps some notes on where he/she fits into the agency. An understanding of the agency chain of command will help you identify further steps you can take if a solution is not reached.

As you work out your step-by-step action plan, jot down the date you expect to take each step. These dates will be approximate since you cannot control the action of the other party but the dates will help you maintain your sense of purpose and direction. Whenever you request something from the other party like an appointment to review a casefile, a meeting or a copy of a policy, specify when you would like a response to your request. Two weeks is a reasonable time within which to expect a response to most requests or at least to expect a written acknowledgement of your request including a commitment to respond by a specified alternate date.

It is a good idea to note down any additional information, material or support you will need to implement you plan and any special considerations or circumstances.

Finally, think about what you will do if your plan is not successful. There are almost always further steps you can take such as dealing with others further up the chain of command, asking for a formal hearing or asking for outside help to name just a few options available to you.

Working out a detailed advocacy plan is a lot of work but it will help you be more effective and it will increase your confidence. You will develop your own short cuts and time savers as you gain experience as an advocate. At the beginning, however, we do not recommend trying to proceed without a plan.

Things to Consider As You Develop Your Plan

Advocacy is accomplished through communication. The communication may be written or spoken. It may be over the telephone or in person. But advocacy always involves communication. Subsequent chapters discuss communication from the advoccate's perspective. Reviewing these chapters will not only help you learn important skills, but will also generate ideas you can use in developing your advocacy plan. Another source of ideas for your plan, is the set of sample advocacy plans at the end of this chapter. If you have difficulty in developing a plan, don't give up. Consult a professional advocate for assistance.

SAMPLE PLANS

Advocacy Planning Guide

Date: ____________________

The problem is: ____

____

____

The ideal solution is: __________________________________

____

____

An alternate acceptable solution is: ____________________

____

____

Who has authority to make changes:

Name: ______________________________ Position: ____________

Agency: ____

Address: ______________________________

____

Telephone: ____________________________

Notes on the chain of command: __________________________

____

____

____

INFORMATION I NEED TO SUPPORT MY VIEWS

Information I already have: ______________________________

____

____

____

____

____

____

____

____

____

Information I still need to obtain: ______________________

____

____

____

____

____

____

____

____

____

My Arguments: ____________________

Arguments the other party may make:	My Counter arguments:
1. ____________	1. ____________
2. ____________	2. ____________
3. ____________	3. ____________

My Plan:

If My Plan Doesn't Work:

Results:

Agreements Reached:

When:

Responsible Person:

Telephone number:

Address:

ADVOCACY PLANNING GUIDE

Sample A

Date: January, 1986

The problem is: My 8 year old son, who is visually impaired and in special education, needs speech therapy. This service was not included in his annual individualized education plan and is not being provided.

The ideal solution is: I want Ryan to receive two half-hour individualized speech therapy sessions from a qualified speech therapist, and one hour of group speech therapy per week.

Alternative solution: I want Ryan to receive two one- hour group speech therapy sessions per week from a qualified speech therapist, and I want a speech therapist to show Ryan's regular classroom teacher how to work with Ryan to improve his speech.

Who has authority to make the changes:

Name: John Grant*

Position: Special Education Director

Agency: Smallville School District

Address: 100 Main
Smallville, MI 49100

Telephone: (517) 891-9444

* = As a result of decision by Ryan's individualized educational planning committee.

Notes on chain of command:

Michigan Dept of Education, Special Education Service Area

to

Intermediate School District - Basset County
Superintendent
Director of Special Education

to

Smallville School District
Superintendent
Director of Special Education Services
Principal
Regular education teacher, special education teachers
Speech therapist, other professionals

Information Needed to Support My Views

Information I Have: * Ryan is eligible for special education based on the fact that he is legally blind. * I have observed that Ryan says words funny. He doesn't pronounce certain letters, especially: l's, r's, s's, t's, th's. He has done this since he learned to talk. * The Michigan Special Education Rules say that speech therapy may be provided as a related service. * These rules also say: (1) related services are those services needed in order for a student to benefit from special education. (2) a student shall be evaluated in all areas of suspected disability. (3) IEPC's determine services needed and IEPC meetings may be convened when necessary. * Last month our family doctor said Ryan has not outgrown his speech problems and suggested I look into speech therapy. * I had a conversation with Ryan's teacher. She said she has noticed Ryan's speech problem. He is becoming reluctant to talk in class because some of his classmates tease him about his speech. *I read an article about children's language development. It said most children outgrow speech problems by the age of five or six. If they don't they should receive speech therapy.

Information I still need: * I need a speech evaluation done on Ryan to see what is recommended. * I must rule out the possibility of a hearing problem - need a hearing test.* I need to know procedures for requesting a new IEPC - consult an advocate - MP&A.

My Arguments: * Ryan will have to work hard for social acceptance and job success because of his visual handicap. A speech deficit will compound the problem. It is correctable and should be treated. * He needs the service to participate fully and benefit from his education - he is decreasing his classroom participation because of embarrassment. * The service is available under special education law. * Ryan's family doctor has recommended it.

Arguments the other party may make:	My Counter Arguments:
1. Ryan will outgrow his speech problem - therapy is not needed.	1. Ryan has not outgrown the problem. Children who outgrow the problem have done so by Ryan's age.
2. No speech problem has has been observed.	2. I have observed the problem: so has Ryan's physician and his teacher.

3. Don't have staff available or money to provide the service.	3. Lack of staff/money is not a valid excuse for not providing a needed service.
4. They'll try to make me feel guilty for asking for too much since Ryan already receives teacher consultant services and adaptive aids for his visual handicap.	4. Services are to be individualized to meet student's needs.

My Plan:

1. Call Ryan's teacher and schedule a teacher conference to discuss the problem. Call tomorrow 1/14.

2. Ask the school to conduct a hearing test and a speech and language evaluation - write letter immediately after teacher conference 1/22.

3. Ask family physician to write a letter recommending evaluation. Call tomorrow 1/14.

4. Call advocate to find out how to ask for a new individualized educational planning committee meeting and to review my advocacy plan. Call tomorrow 1/14.

5. Ask for a new IEPC meeting. Write letter? 1/15.

6. I'll tape record Ryan's speech. Tonight.

7. Arrange for someone to attend the IEPC meeting with me for moral support - Call Mrs. Jones, Parent Advisory Committee representative 1/15.

8. Attend IEPC meeting. Mrs. Jones will take notes so I can listen actively - 2/15 (?).

9. Take new service plan home to review before signing.

10. Sign plan if acceptable.

11. Follow-up to make sure services are delivered.

--talk to Ryan.
--talk to teacher.
--visit on a scheduled therapy day.

If plan doesn't work:

--Call advocate for ideas.
--Ask for another IEPC meeting.
--Ask for a hearing.

ADVOCACY PLANNING GUIDE

Sample B

Date: February, 1986

The problem is: I want to attend and to testify at the Public Service Commission's (PSC) public hearing on proposed rate increases for electric service. I need an interreter since I am deaf. I called the Public Service Commission but they said they did not know anything about providing interpreters.

My ideal solution: The Public Service Commission should provide a certified sign language interpreter and should write a policy about providing interpreters at public hearings so this does not happen again.

Alternate Solution: They should write a policy about providing interpreters at public hearings so this does not happen again.

Who has authority to make changes:

Name: Don't know--see information I need. Position ___________

Agency: Michigan Public Service Commission

Address: 6545 Mercantile Way, Box 30221
Lansing, MI 48909

Telephone: (517) 373-3244

Information I Need

Information I Already Have: *Two laws say that interpreters must be provided to deaf persons at public hearings. *Michigan Handicapper Civil Rights Act, Article 3 - Public Accommodations/Public Services (MCLA 37.1302). *Deaf Person's Interpreter Act (MCLA 393.501). *The event involved is a public hearing--I have the notice which was published in the newspaper. I am deaf. I have reports to verify that. *The Public Service Commission (PSC) is responsible for providing the interpreter since it is holding the hearing. *I gave them advance notice that I needed an interpreter - Notes in my records of the call. *I can file a complaint with the Michigan Department of Civil Rights if my rights are violated. *The Division for the Deaf and Deafened (DDD) can provide information and technical assistance perhaps advocacy, in situations like this.

Information I still need: *Is there an informal grievance or complaint procedure I can use with the PSC? *Who would I contact there about this? *Who within the PSC can authorize for interpreter services? *What is the chain of command at the PSC?

Arguments the other party may make:	My Counter Arguements:
1. It's not their responsibility.	1. The law says it is their responsibility.
2. They don't know where to find an interpreter.	2. The Division for the Deaf and Deafened (DDD) can help locate an interpreter. The PSC should establish procedures for fulfilling their responsibilities.
3. They can't afford to pay for an interpreter.	3. Lack of funds is not a valid excuse.
4. I should bring my own interpreter-they may offer to pay.	4. They are responsible for providing an interpreter -it is my civil right. I do not have the money.

My Plan:

1. Call the Public Service Commission (PSC) and restate my request for an interpreter. I will have my information and copies of laws handy - today.

2. If PSC says they will provide an interpreter I will ask who will be responsible for this. I will provide information on the type of interpreter I need and I will refer them to the Division of the Deaf and Deafened (DDD) for help in locating an interpreter - today.

3. If PSC says they will not provide an interpreter of if they are noncommital, I will ask for information on the chain of command and on complaint procedures. I will ask to speak to the person next in the chain of command - today.

4. I will speak to the person briefly about my request and ask for a meeting to discuss my request. I will ask for an interpreter to be present at this meeting and I will ask someone from the Division of Deaf and Deafened to be present to help me - today.

5. I will call the DDD to discuss my situation and ask someone to come to the meeting - today.

6. I will attend the meeting and present my arguments, listen to PSC's response and respond to them (within the week).

If my plan doesn't work:

I will file a civil rights complaint with the Michigan Department of Civil Rights. I will ask that a policy on interpreters be developed by the PSC so this doesn't happen again.

CHAPTER VII

ASSERTIVENESS

The Relationship Between Assertiveness and Advocacy.

Assertiveness is a way of thinking and behaving that allows a person to stand up for his or her rights while respecting the rights of others. Nonassertive people may be passive or aggressive. Passive individuals are not committed to their own rights and are more likely to allow others to infringe on their rights than to stand up and speak out. On the other hand, aggressive persons are very likely to defend their own rights and work to achieve their own goals but are also likely to disregard the rights of others.

Assertive attitudes and behaviors are at the heart of effective advocacy. A person with an assertive attitude recognizes that each individual has rights. These rights include not only legal rights but also rights to individuality, to have and express personal preferences, feelings and opinions. The assertive individual not only believes in his or her rights but is committed to preserving those rights. An assertive attitude is important in recognizing that rights are being violated. The passive person is so concerned with being liked and accepted that he or she may never recognize the need to advocate. The aggressive person is almost always tuned-in to his or her rights but is not a good problem solver since he or she is quick to blame and attack others.

Many people feel they are not assertive. If you are one of them, now is the time to start changing this. Perhaps you, at the present time, are not as assertive as you could be. Assertiveness is a matter of degree. You can become more assertive than you are now by increasing your understanding of the idea and by practicing assertive behaviors.

Understanding Assertiveness

In this section we will describe several aspects of assertiveness and contrast assertiveness with passiveness and aggressiveness.

Relationship between self and others

The passive person is preoccupied with being liked and accepted. However, because the passive person usually does not accept him or herself, this person is afraid to speak up for fear of rejection. Because the passive person gives the power over self acceptance to others, he or she feels powerless.

The aggressive person focuses on his or her own desires and how others may be used to achieve them. While the aggressive person usually appears to value him or herself highly, little regard is given to others, their feelings or rights.

The assertive person values him or herself but also values others. The assertive person does not necessarily like everyone nor desire to be liked by everyone, but she or he does respect others and their rights.

Listening Behaviors

A person who is passive listens to others but does not always hear accurately because he or she often feels too anxious to concentrate. Furthermore, a passive person is unlikely to analyze information in terms of his or her own values because those values become lost in the attempt to win acceptance from others.

The aggressive person may allow others time to speak but usually doesn't listen well. He or she is too preoccupied with his or her own perspective. The aggressive person may also be a poor listener because he or she feels very angry and defensive.

The assertive person is more likely to be a good listener than either the passive or aggressive person. The assertive person is able to be more open to information and to be more effective in analyzing and evaluating the value of what he or she hears and sees. The ability to listen, and to gather and analyze information is important in the advocacy process.

Motivations

The passive person is motivated mainly by a desire for acceptance and security. Although he or she frequently feels anxious, this person is not likely to take risks. The aggressive person is motivated by a desire to control and dominate others. He or she frequently feels angry, insecure and defensive. The assertive person has a wider range of motivations and emotional states. He or she may be concerned with self-understanding and growth, with development of his or her abilities and with relating to other persons. He or she usually is able to exert more control over emotions and to work for problem solutions that benefit all parties.

Behaviors

The behaviors of a passive person are usually designed to hide individuality. The individual may actually look and act passively but could also look and act conventionally - so conventionally he or she is never noticed.

The behaviors of the aggressive person are designed to intimidate and overpower. There's little chance that this person will go unnoticed. "Pushy" is a good description of this person's loud and insistent voice and large, sometimes grandiose, gestures.

The assertive person's behaviors are designed to promote communication and problem solving. This person uses a variety of behaviors depending on the situation. In general, the assertive person appears energetic yet relaxed.

Below is a short quiz designed to help you gain an idea of how assertive you are at this time.

ASSERTIVENESS QUIZ

1. Do you buy things you do not want because you are afraid to say no to the salesperson? Yes No
2. When you do not understand the meaning of a word, do you ask about it? Yes No
3. Do you feel responsible when things go wrong, even if it is not your fault? Yes No
4. Do you look directly at others when you talk to them? Yes No
5. Do people often ask you to speak more loudly in order to be heard? Yes No
6. Do you feel intimidated by people in authority? Yes No
7. Do you generally have good posture? Yes No
8. Do you ever feel so angry you could scream? Yes No
9. Do you know how to ask for help without feeling dependent? Yes No
10. If someone cuts in front of you in a line, do you usually tell them off? Yes No

Assertive Responses

1. No
2. Yes
3. No
4. Yes
5. No
6. No
7. Yes
8. No
9. Yes
10. No

Explanation of answers to the Assertiveness Quiz

1. The assertive person is not afraid to say no. She or he feels free to make choices.

2. The assertive person takes responsibility for getting his or her needs met. Fear of seeming ignorant does not prevent the assertive person from asking questions.

3. The assertive person takes responsibility for his or her own behavior but does not take responsibility for the behavior of others or for situations which are beyond his or her control. To feel responsible for things beyond your control leads to unnecessary feelings of guilt.

4. Direct eye contact is assertive and suggests sincerity, self-confidence and the expectation that others will listen.

5. An assertive person wants to be heard.

6. An assertive person does not allow status to intimidate him or her.

7. Good posture communicates a positive self-image. When posture is limited by a disability, good eye contact and facial expression can be used to express a positive self-image.

8. The assertive person works to get his or her needs met and does not let situations build to the point of crisis.

9. The assertive person is able to ask for help without feeling dependent because he or she maintains a strong sense of self-worth and self-respect.

10. Telling someone off is an angry, aggressive response. The assertive person would state that he or she is irritated by the unfairness and ask the person to move to the end of the line.

Assertive Listening

Assertive listening is one of the most important advocacy skills we will discuss. The goals of assertive listening are: (1) to let the other know that you want to understand his or her point of view; (2) to understand accurately what another is saying; and (3) to let the other know that he or she has been understood. Remember that understanding is different from agreement. You can understand what another is saying but still disagree with him or her.

You can let others know you are interested in hearing and understanding their points of view in several ways. You can tell them you are interested. Here are some examples of how you could phrase such a statement:

* I'd like to hear your views on ______________________________.
* I'd like to understand your views on _________________________. Could you tell me about them?
* I'm confused about your stand on ___________________________. Would you tell me more about how you see the situation?
* I think we are approaching this from two different perspectives. What does the situation look like from your perspective?
* I'd like to hear your thoughts on ___________________________.

Looking directly at the other shows you are giving him or her your attention. Leaning forward slightly communicates interest, while a relaxed, open posture communicates receptiveness to what the other party is saying.

Listening for accuracy takes concentration and requires you to give your full attention to what the other is saying. It is easier to listen for accuracy when you feel relaxed. If you are tense and your own thoughts are racing, excuse yourself for a minute and go to another room. Take a few deep breaths to relax and clear your mind before returning. Ask questions as they come up, especially if the answers are important to understanding additional points the other party is discussing. Saying "um hum" and nodding your head slightly will encourage the other to continue talking. Most people will discontinue talking without these mild encouragements.

You can test whether or not you have understood the other party by summarizing your understanding of what was said and asking for verification. This not only lets you know whether you have understood the other correctly, it also lets the other person know they have been understood. Some problem solving or negotiation sessions get stuck because people don't realize that they understand one another. Many times the issue is not confusion, but disagreement about what to do about the problem. Working out solutions is different from establishing an understanding and some issues remain unresolved because parties never get past the stage of establishing that all viewpoints are understood. Below are some examples of language you can use to test for understanding.

If I understand you correctly, ___________________________________. Is that what you meant?

I heard you say ___________________________________. Did I understand you correctly?

Your view is ___________________________________. Is that right?

Nonverbal Assertiveness

Even when we are silent we communicate a lot - through our eyes, facial expression, posture, gestures and personal appearance. Through these nonverbal behaviors we communicate who we are and how we feel. Others draw conclusions about our sincerity, credibility and emotional state based on our nonverbal behavior. Poor eye contact, slouching, nervous gestures and other nonassertive behaviors can convince others that what we have to say can be safely ignored. Awareness of our nonverbal behaviors is an important advocacy tool.

Nonverbal behaviors are harder to control than verbal behaviors, but with awareness and practice you can become effective in communicating nonverbally as well as verbally.

Elements of Nonverbal Behavior

1. Eye contact. Eye contact means looking directly at another, focusing on his or her eyes. Direct eye contact is assertive. Children often play at seeing who can stare the other down. The one who can maintain eye contact the longest wins and gains a sense of power. We aren't suggesting you try to out stare others, but looking directly at another while you are e

speaking strongly suggests, even demands, that you be listened to and taken seriously. Looking down while speaking to another suggests timidity and weakens you in the eyes of others. Looking to the side as you speak suggests avoidance and insincerity and jeopardizes your credibility.

Maintaining eye contact while the other is speaking shows your interest in listening. There are times when you will want to minimize eye contact while others are speaking, perhaps to avoid revealing your reaction to what is said or to give you time to think. When this occurs, concentrate on note taking since this also gives the impression that you are listening.

2. Posture. The moment you walk into a room, your posture and carriage communicate messages about your confidence, how you expect to relate to others, your energy level and emotional state. Slouching may say "Don't notice me" or "I'm tired and can be easily worn down" or "I'm not interested in being here". Slouching does not invite the other to take you seriously. A tense and rigid posture communicates you are in a heightened emotional state. It may be interpreted as anxiety or anger depending on your other nonverbal behaviors. This kind of posture makes you look out of control. An erect and relaxed posture while standing and sitting communicates confidence,

self-control, energy and an expectation that you be taken seriously.

When sitting, leaning forward slightly communicates interest and a sense of purpose. Leaning back communicates disinterest or disagreement. Crossing your arms and legs suggests a tense and closed attitude while uncrossed arms and legs suggests a relaxed and open attitude.

3. Facial expression. We say a lot through our facial expressions. Our face tells others the degree to which we are alert, interested, in agreement, or relaxed. It reveals the types of emotions we feel. It is best to keep your facial expression as neutral as possible.

4. Gestures. Gestures can be used to accentuate and support your message or to distract and discredit. Nervous fidgeting and tense jerky movements are distracting. These types of gestures and movements make you look out of control and seriously diminish your persuasive power. If you have trouble controlling nervous and fidgety movements, channel your nervous energy by taking notes. Hand and arm movements can be used to emphasize what you say. Don't emphasize everything, however. Be judicious in your use of gestures. Keep your gestures relaxed,

fluid and moderate in size. Gestures which are too large make you look grandiose while gestures which are too small make you look nervous.

5. Personal Appearance. Whether we like it or not, how we dress affects credibility. It also affects how we feel. Being extremely overdressed or underdressed in relation to others makes most people uncomfortable. We aren't going to offer any hard and fast rules about how to dress, but you may want to bear in mind that if you meet with an administrator, he or she will be dressed for business. Since in the professional world, the way in which you dress does carry messages about power, it is best to dress neatly, conservatively and as professionally as possible.

6. Tone of Voice. There are many aspects of voice that affect the impact your words have on others. The most important of these and the easiest to control are loudness and speed. Nervousness can make us speak too softly to be heard or so loudly that we distract from our message. Speak loudly and slowly enough to be heard and understood. It is also important to control how you end your sentences. Raising the pitch of your voice at the end of a sentence makes the sentence sound like a question. A slight lowering of pitch at the end of a sentence makes it sound like a statement. Make your statements sound like statements in order to strengthen your message.

Building Nonverbal Assertiveness

Building nonverbal assertiveness takes patience because nonverbal behaviors are usually automatic and we are less aware of them than we are of our verbal behaviors. Here are two ideas you can use to build more assertive behaviors.

1. To increase your awareness and control, stand in front of a mirror and try to look as unassertive as you possibly can. Slouch, let your chest cave-in, droop your shoulders, hang your head. Try for a really timid facial expression. Now talk to yourself in the mirror. Mumble while talking and try to make everything you say sound like a question. Now work your way gradually into an assertive posture. Straighten up, look yourself directly in the eye, relax your body and breathe fully and naturally. Smile at yourself and try to give a welcoming look at yourself in the mirror. Compliment yourself out loud, then neutralize your expression and recite your name and address in a calm persuasive tone. Go back and forth between the unassertive and assertive demeanors several times. Decide you really like looking and sounding assertive.

2. Sit down, close your eyes and relax. Take several slow deep breaths to relax. When you feel relaxed, visualize yourself. Examine your image of yourself. Is your image assertive looking? Change this image to make it look assertive - as assertive as you possibly can. Decide you like this self-image. Now imagine you are having a conversation about how assertive you are becoming. Do you sound assertive? Make yourself sound more assertive by speaking calmly, clearly and with energy. Compliment yourself on how assertive you have become.

Verbal Assertiveness

How do you say what you want to say and make it sound assertive? That's what this section is about.

Simple Assertion

The simple assertion is a basic building block of assertive communication. It is a plain and straightforward sentence in which you state an opinion, belief, or request. In making a simple assertion, you do not attempt to explain or justify. The following statements are simple assertions:

- I would like a copy of the file.
- I would like to speak first.
- I believe your procedure violates state law.
- You did not answer my question.

Simple assertive responses can be used in a wide range of situations. Here are some examples.

Someone cuts in front of you in a supermarket line.

Simple assertion: Please move to the back of the line.

You are trying to gather the family together to eat dinner but your four-year-old wants to watch television.

Simple assertion: I want you to come to the table now.

You have just asked the special education director at your child's school when they will implement services that are described in your child's individualized educational plan. They are already two weeks behind. He says they are working on it.

Simple assertion: You did not answer my question.

Here are three more situations you can use to practice simple assertions.

Your television set was just returned from the repair shop. The technician said the problem has been corrected but when you try the set at home you find that the problem still exists.

Your simple assertion to the technician: ______________

____

Your family doctor has just switched your son to a new medication. You like the old medication better because it has fewer side effects.

Your simple assertion to the doctor: ____________________

____

You want to apply for Social Security Disability Benefits. The receptionist at the Social Security office discourages you from applying because you do not look disabled.

Your simple assertion to the receptionist: ______________

____

Acknowledgement and Assertion

The use of acknowledgement and assertion allows you to show that you understand the other's perspective while asserting your own needs. This assertive technique is useful when others seem to feel you do not understand or are not listening. Here are some examples of the acknowledgement and assertion technique.

* I understand that you are worried about how your customers will react to seeing a person with a visible handicap, but my friend and I have reservations here and we wish to eat lunch here.

* I understand that you are worried about how the school district will fund occupational therapy services, but my son needs these services in order to benefit from his educational program.

* I can see that you are uncomfortable with our position, but we feel our daughter does not need a guardian at this time.

Acknowledging the feelings and views of others helps build rapport and helps prevent discussions from becoming too adversarial. Use the sample situations below to practice formulating a response that acknowledges the feelings and/or views of the other and asserts your own needs.

* Your son has asked to borrow the family car tonight. You and your husband have plans for the evening and need the car. When you tell your son that he cannot use the car, he gets very angry. He says he needs the car more than you and suggests that you cancel your plans. Write a response that would acknowledge your son's anger and assert your intention to use the car. ______

____

____

____

* Your wheelchair is in the repair shop. You had been told that the repairs would be completed by this afternoon. You are very eager to have your chair back since the loaner wheelchair you are using is older, heavier and harder to maneuver than your own chair. When you call to confirm that your wheelchair is ready, the receptionist informs you that the chair is not ready. "We have been incredibly busy this week and have not had a chance to take a look at your chair yet," she explains.

Write a response that would acknowledge the shop's state of overwork and assert your desire for prompt service.__________

____

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____

Repeated Assertion

Sometimes it is necessary to repeat an assertion several times. This is called repeated assertion. Repeated assertion is useful in at least two types of situations. When you do not get a response to a request, you may want to repeat the request until you get a response, as shown in the example below.

Example: Allen, who has cerebral palsy, walked into a hamburger shop and sat down at the lunch counter. It was not crowded and the waitress was leaning on the counter chatting with another customer. She looked up from her conversation and stared at Allen for a minute and then returned to her conversation. Allen waited about ten minutes and still the waitress did not approach to take his order. Allen said, "Waitress, I am ready to order now."

He got no response.

Allen said, "Waitress, I am ready to order now."

The waitress continued her conversation . Allen repeated a third time, "Waitress, I am ready to order now."

The waitress approached Allen to take his order.

Sometimes others ignore us hoping we will give up and go away. Allen showed he was unwilling to be ignored by repeating his request until the waitress responded.

A repeated assertion is also useful when the other party tries to shift the topic of conversation in order to sidetrack you, or seems to be unnecessarily complicating the situation. The example below illustrates how a repeated assertion can be used in this kind of situation.

Example:

Mrs. Adams: I want to review my son's educational record.

Principal: Those records are very complicated. I don't think you would understand them.

Mrs. Adams: I am very interested in reviewing my son's educational records.

Principal: I am sure I can answer any questions you have about your son's education.

Mrs. Adams: I have a right to see my son's educational records and I would like to do so.

Mrs. Adams did not let herself get drawn into a discussion of whether or not the records were complicated, whether she would be able to understand them or whether the principal could answer her questions. She stuck to the point and reiterated her request to see the records. Mrs. Adams did not use exactly the same words in each of her assertions. This is not necessary. The point of using a repeated assertion is to stick to the point and show that you are not willing to be ignored or sidetracked.

Agreement and Assertion

Another assertive technique is to agree with those statements made by another person that are true while continuing to assert your point of view. This is called agreement and assertion. Use of this technique shows that you are listening and willing to work with the other, while allowing you to stick to the point.

Example:

Sandra: I would like to receive training to become a school teacher.

Vocational Counselor: It is very hard to get a teaching job. There are already too many teachers.

Sandra: I know it will be difficult to get a job teaching, but I know I have a talent for teaching and this is what I want to do.

Vocational Counselor: Your disability would make it even harder to compete for a job as a teacher. Have you considered other types of work?

Sandra: I realize that my disability will be a factor in getting a job no matter what sort of job I look for. Teaching is what I want to do.

In the example above, Sandra agreed with the counselor's statements and by doing so showed that she realized that she would face a difficult challenge in seeking a teaching job. She also showed determination and a commitment to meeting the challenge.

Becoming more assertive is one of the most valuable skills you will ever develop since it gives you the means to control your life. Developing assertiveness takes practice and support from others. If you are just beginning to develop your assertiveness skills you may want to take an adult education course in assertiveness at a local school or community college or through one of the many groups and associations that offer such training.

CHAPTER VIII

Negotiation and Communication in Meetings

The resolution of many advocacy problems will involve one or more meetings with service providers and administrators. You will use all of the skills we have discussed; problem analysis, information gathering, action planning and assertive communication in preparing for and participating in these meetings. In this chapter we will discuss additional advocacy techniques and pointers that can help you become a more successful advocate in meetings and negotiations.

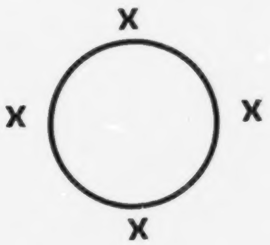
Whose Territory

Where a meeting is held will have a subtle but powerful impact on you and everyone else who participates. People generally feel more comfortable and in control of the situation when they are in their own territory. Conversely they feel less comfort and control when they are in someone else's territory. Potential discomfort over being on someone else's turf can be decreased by increasing familiarity with the individuals you will negotiate with and increasing familiarity with the site of the proposed meeting.

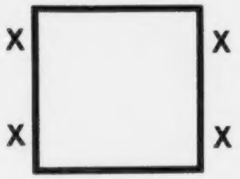
If you have control over where the meeting is held, request that it take place in your home. Service providers seldom will agree to this, not so much because it is inconvenient or expensive, but because of the sense of control they will lose by meeting on your territory. If it is not possible to meet on your own territory, arrange to meet at a neutral location, such as a library, church or public building. Any conference room is preferable to meeting in a provider's office.

It's a good idea to arrive at the meeting location early. This will give you a chance to become familiar with and feel more comfortable in the meeting space. Secondly, it will give you some control over the seating arrangement. Some seating arrangements create a sense of equality among participants at a meeting whereas others create a power imbalance.

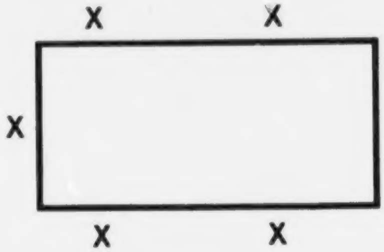
A round table has no head seat and thus creates a feeling of equality. Since there are no sides to a round table it also minimizes an "us versus them" atmosphere.



A square table can also be used to equalize power. Although it is likely to enhance the feeling of taking sides.



The head chair at an oblong table connotes power. If you are faced with an oblong table, sit in the head chair if possible.



The person who sits behind a desk during a meeting enhances his or her power considerably. In addition, the desk can create a sense of defensiveness and act as a barrier to open communication. If you can, try to get the other party out from behind his or her desk in order to equalize the power.

The Numbers Game

Before the meeting, find out who the other party plans to have present. You will want to know their names and roles within the organization. If the other side plans to have several people present, bring several people with you. Equalizing the number of people representing each side will help to equalize the power. It will also allow you to assign tasks to your supporters, taking some of the pressure off of you.

Controlling the Agenda

Service providers and administrators attend a lot of business meetings and they are accustomed to using an agenda to guide what takes place at the meeting. The other party will have an agenda or set of objectives they wish to accomplish and a strategy for accomplishing their objectives. They may not describe this agenda to you but they will have one nonetheless.

You must have a set of objectives and a plan to accomplish them also. If you do not, the other party will control the content and the outcome of the meeting. Use an advocacy plan as discussed in chapter six to develop your objectives and strategy for the meeting.

When you get to the meeting, ask that an agenda be developed to which all parties agree. The agenda should state the issues to be discussed and the order in which they will be discussed. As the agenda is being developed, it is a good idea to tackle less controversial issues first if there are several issues to be decided. This will give everyone a sense of progress and accomplishment and will create a more cooperative basis for tackling more troublesome issues later.

It is also a good idea to agree on how long the meeting will last since you or other participants may have commitments later in the day. If time constraints will not allow all issues to be dealt with, arrange for an additional meeting so that you will not be pressured into unacceptable compromises because of time limitations.

Time to Think

As you developed your advocacy plan you listed your objectives, organized your information, identified the types of arguments the other party might use and thought of how you might respond to those arguments. Despite all of your preparation, surprises will occur. The other party may propose arguments you hadn't thought about, ask for information you don't have or propose a solution you are not sure you are willing to try. If this occurs, ask for a short break to allow time to think about how you want to respond. It is also important to ask for a break if you feel you are losing emotional control. You will not negotiate at your best when your thinking is clouded by intense anger, anxiety or other emotions. Resist the temptation to simply walk out since you gain nothing by this and will damage your credibility seriously. Asking for a break is perfectly acceptable: so is asking that the meeting be adjourned until a later time. If you decide to take a break, leave the room, otherwise the other party is likely to engage you in small talk and deprive you of your opportunity to plan your next step.

Don't Get Caught In These Traps

There are several strategies that are commonly used by service providers and administrators because they are very effective in throwing advocates off track. Just being aware of these strategies will better prepare you to handle them if they are used.

Use of jargon: It is common for professionals to use jargon. By this we mean technical terms, specialized words or abbreviations that are not likely to be used in everyday conversation of the average person. In negotiations, professionals may intentionally use a lot of jargon in order to make nonprofessionals feel ignorant, to keep them out of the conversation or to diminish their credibility.

Resist the temptation to pretend you understand jargon. Ask that all terms you don't understand be defined in plain English and ask others to avoid using abbreviations with which you are not familiar. It is unfair to expect the average person to understand jargon. Do not allow yourself to feel less competent or less powerful just because you aren't familiar with certain types of specialized jargon.

It's also important to learn to say "I don't know" comfortably. You should not be expected to know everything although, at times, you may be asked questions you aren't expected to know the answers to in order to throw you off guard.

Creating Guilt: If you are beginning to feel it is your fault that the problem exists in the first place, you are getting caught in a guilt trap. If the other party is able to make you feel responsible for the problem, he or she is getting ready to convince you that you, and you alone, are responsible for the solution. Resist this common and usually effective counter advocacy strategy. Hopefully you have researched and identified your rights and the responsibilities of the other party. Suggestions that you are a bad person or a bad parent are irrelevant and you should say so.

Use of Ultimatums: The use of ultimatums is unwise. Don't do it. An ultimatum is the use of an uncompromising, "take-it-or-leave-it" position. It is likely to cut off valuable options and will definitely make you appear unreasonable, creating sympathy for the other party. Skilled advocates and negotiators do not use ultimatums.

If the other party issues an ultimatum, question them about it. Ask what options and alternatives were considered before deciding on their position. Suggest that perhaps not all options were considered. Suggest that there may be additional positions to consider. Ask if there are any exceptions to the ultimatum. Try to think of examples where they would be likely to make exceptions to the ultimatum. Your goal in asking questions is to show that you are unwilling to accept a "take-it-or-leave-it" offer and want to explore additional alternatives. Furthermore, you want to joggle the other party's thinking so that they also are willing to look at possibilities beyond the ultimatum they have issued.

Communication and negotiation in meetings is complex, challenging and fascinating. We suggest that you build your own skills by attending meetings with other advocates and playing the role of observer and notetaker. As an observer, the pressure will be off you and you will have more freedom to analyze and learn. As a side benefit, your presence provides support to the advocate and he or she may return the favor to you when it is your turn to advocate.

CHAPTER IX

Writing Letters

We have all written letters -- writing letters is nothing new. However, sometimes the idea of writing a letter as an advocate makes it impossible for intelligent people to put words on paper. This problem arises when a letter written as part of an advocacy effort is seen as radically different from a "regular" letter. The letters you will write as an advocate are simply business letters. Even if you have never written a business letter, you've read many and you know what they look like. A second barrier that makes an advocacy letter seem difficult to write is the notion that you must tell your entire story in the letter. This notion makes the task of writing seem overwhelming. But in fact, it is unwise to tell your whole story in a letter. The idea that you must tell the whole story arises when you feel you must justify your position or request. This usually is not necessary.

As an advocate, most of your letters will be written to accomplish a fairly simple and specific objective such as: to request a meeting in which the problem will be discussed, to request information, to make an appointment to review a case file, or to thank others for their cooperation. A letter is the best way to make such requests, since it is more likely to get a response than a telephone request is. Such letters should be short and to the point. There will, of course, be some occasions when your objective requires a longer letter with more detail. For example, a letter filing a formal complaint, a letter to your congressperson or to the editor of a newspaper may require more detail. But these letters too should be as concise as possible.

Materials and Style

Your advocacy letters are business letters and should be consistent with standards for good business correspondence. Save your prettiest stationery for writing to your friends. Instead use plain white typing paper or simple stationery with your name and address imprinted. To ensure that your letter is legible and looks professional, type it or ask a friend to type it for you. Use a business style in setting up your letter. If you aren't familiar with business styles, study the sample letters in this chapter and use them as a model for setting up your letter. When your letter is finished, check it very carefully to make sure you have not made any errors in spelling, grammar, punctuation or in typing. Careless errors will decrease your credibility and may cause your reader to conclude that you are not serious enough about your request to ensure your letter is correct.

Deciding To Whom To send The Letter.

A response to your letter will be delayed if you send it to the wrong person or if you address to an agency rather than to a specific person within the agency. If you are unsure as to whom the letter should be addressed, call the agency and ask the receptionist to give you the name, correct spelling and title of the person who handles the type of request you plan to make in your letter. Make sure you have the correct address and a telephone number to use in following up on your letter.

Writing the Letter

It's a good idea to make a short outline or list of points you want to include before you write your final copy. This will help you organize your thoughts and will result in a well organized letter. It will also help ensure that you don't forget anything important.

The outline should contain the following points:

1. A sentence or two that states your purpose for writing the letter.
2. Sentences that provide further detail on your request.

3. A statement summarizing your request and asking for a response to your letter. Make sure to include the date by which you want your response and information on how you want to be contacted.

Always make sure to keep a copy of the letter for your records. We recommend that you send the letter by certified mail and request a return receipt so that you know the letter was delivered and accepted. Keep the receipt as part of your record. It's also a good idea to note the date by which you expect your reply on your calendar. If you do not receive a reply by the date requested, call to find out when the other party will respond to your request. If necessary, write a second letter pointing out the fact that you have made a request but have not yet received a reply. You may want to send copies of your letters to advocacy agencies and to your legislators and congresspersons since this creates an incentive for the other party to respond to you. On the following pages are several sample letters written as part of an advocacy plan.

Sample Letter

Mrs. Martha Solem
8121 E. Oak
Grand Oaks, MI 46502
(608) 339-8921
March 1, 1986

James R. Bissel
Director of Special Education
Mt. Hope School District
1802 E. Sandevaul
Grand Oaks, MI 46501

Dear Mr. Bissel:

I am the parent of Ryan Solem, a first grader at Central School. I suspect that Ryan may have a learning disability. Please evaluate Ryan to see if he is eligible for special education services.

Please tell me in writing when the evaluation will be done and who will perform the evaluation so I can give written consent. I look forward to hearing from you within a week regarding your plans for Ryans's evaluation. Please send your letter to me at the address above.

Thank you for your cooperation in ensuring the best education for my son.

Sincerely,

Martha Solem

cc: file

James Strong
5 Adams Lane, Apt. #6
Wauwacosta, MI 47811
(616) 981-0020
April 6, 1986

Ms. Silvia Pate, District Manager
Michigan Rehabilitation Services
Landville, MI 47811

Dear Ms. Pate:

I am a client of your office. I am interested in receiving a copy of your agency's written policy on financial assistance for clients who wish to earn a college degree. I understand that this policy is a public document and that I have a right to review and to receive a copy of it under the Michigan Freedom of Information Act (MCLA 15.231 et seq). I would be happy to pay a reasonable cost to cover xeroxing and postage, if this is necessary.

Please send the information to me at the address above. Thank you for your prompt response to my request. I look forward to hearing from you by April 20, 1986.

Sincerely,

James Strong

cc: file

Sharon Wright
301 S. Mills Rd.
Johnston, MI 41399
(313) 622-1111
May 8, 1986

Mary Hill, Conference Coordinator
Michigan Advocacy Agency
100 Second Ave., Suite 3
Best City, MI 48103

Dear Mrs. Hill:

I am interested in attending your conference, entitled "Advocacy for the 80's", scheduled for June 15, 1986 in Best City. I have enclosed a completed registration form and conference fee.

Your registration form does not provide a space for registrants to request a reasonable accommodation needed because of a handicap. I am deaf and need interpreter services provided at your conference. The interpreters should be certified in American Sign Language.

Please send me written confirmation that you will provide interpreter services for me at your conference. Your letter should be sent to me at the above address.

I am very excited about the opportunity to attend your conference and look forward to receiving your letter within the next two weeks. Thank you for your assistance.

Very truly yours,

Sharon Wright

cc: file

CHAPTER X

Follow-up

Telephone calls have been made, meetings held and agreements reached, but your advocacy is not finished yet. You must always follow-up to make sure that everyone does his/her part to make changes to which they have agreed. Previous chapters recommended that agreements include a target date for all actions that will be taken and a clear understanding of who is responsible for each action. Mark these dates on your calendar and check to make sure that things are done on schedule and are done according to agreements reached.

If you find everything is in place, send thank you letters expressing appreciation for cooperation, since in many situations, the party you have confronted in your advocacy is someone you will need to work with in the future.

If the changes agreed to have not been made as scheduled, call to find out why they haven't been made. Do not settle for a vague response like, "we are working on it." Request a new date and send a letter documenting the new agreement.

CHAPTER XI

Systems Advocacy

Systems advocacy is an effort to change policies, rules or laws which determine how services are provided. Whereas previous chapters have dealt with individual advocacy, this chapter will focus on changing systems. There are similarities between the two types of advocacy but there are also important differences. Both types of advocacy involve use of the five phases of problem solving: problem definition, information gathering, advocacy planning, assertive communication and follow-up. While individual advocacy focuses on changing the situation of one person to protect his or her rights or to improve individual services, systems advocacy works to change the situations of a whole group of persons who share a similar problem or to change a service system. Because systems advocacy benefits many people and strives to prevent problems, it is definitely a worthwhile effort.

Because systems advocacy works to cause change in organizations, service systems or laws, it requires a long-term, sustained effort by a number of people. It is harder to change how an organization or system treats a whole group of persons than it is to change a decision made by one person about the situation of another. Although it is more work, a systems advocacy effort is needed when policies or laws cause the same problem for many people and the problems are expected to keep recurring.

Systems advocacy is generally used to change the policies of agencies, organizations or departments which are part of government or are established by government grants or contracts and operated under laws or governmental rules and policies. These are not profit making businesses and you can't just take your business elsewhere if you aren't happy with the service. The advocacy effort could be directed at a local, state or national agency and it could be directed at changing a written or unwritten policy or at changing a law. Where the effort is directed will depend on the nature of the problem and which organization has authority over the problem area.

The first step in systems advocacy is to find others who are experiencing the same problem that you are. The group does not have to be large - at least at this point. A small core group can involve others to support its position later. The most important considerations are that the members of the group agree on the nature of the problem and are committed to a long-term effort to change the situation. Finding interested group members is not hard. People often enjoy working as a team toward a common goal. The tough problem is keeping people involved over a long period of time.

Keeping members involved requires that all feel a sense of purpose. To create this sense of purpose, there must be clear and specific goals that are achievable in a reasonable amount of time and whose achievement will affect people's lives. If there are many goals, they should be prioritized and worked on one at a time. Otherwise, members will lose their sense of purpose. So, the first task of the group is to define the problem in specific terms and to set a goal that, when accomplished, will help resolve that problem. If the group has more than one goal, start by working on the one that has the greatest potential for successful achievement since success will solidify the group and create motivation for continued efforts.

The next step in your systems work is to gather information. The information needed is primarily the same type needed to solve individual advocacy problems. Which agency has authority to make needed changes? What laws, rules and policies govern the actions of the agency? What rights and complaint procedures exist? What facts support the need for change? It is very important to learn as much as possible about the organization you wish to change. What is the formal hierachy?

How are changes made within the organization? Who has power? Who has credibility? How does the organization view itself?

Since organizations are extremely resistant to change, you must identify ways in which the organization could benefit from making the change. Causing the organization great discomfort and public embarassment is usually not sufficient to cause real change. Organizations have great stability and can weather very heavy stresses. In fact, organizations typically react to advocacy efforts by doing nothing, they just wait until advocates become tired and give up their change efforts. To create real change, you must also create positive incentives that make the change you are trying to achieve attractive to the organization.

To create a positive motivation for change, you've got to get to know the organization well. Attend advisory committee meetings, public hearings and conferences where you can meet staff of the organization. Become familiar with other organizations and key individuals with whom your target organization relates. Use your knowledge of these related organizations to increase your knowledge of your target organization.

A key element of success is the creation of a visible and credible image for your group. You can increase the visibility of your group in a number of ways. The efforts you make to become familiar with your target organization through attendance at advisory committee meetings, public hearings and conferences will help create visibility. So will careful use of media, such as appearances on radio or television talk shows, news and human interest newspaper articles, letters to the editor and speeches to civic groups.

The visible image you create for your group must be credible to have impact, otherwise you run the risk of being seen as cranks and troublemakers. Knowledgeability about your issue is critical to creating credibility. This means knowing both sides of the issues thoroughly -- being able to articulate your point of view and being able to anticipate and respond to arguments from the other side. Commitment to long-term effort to create change is also important to your credibility. If your effort is seen as a quick, "hit and run," maneuver your target organization will decide to simply wait until you go away. In addition, you must associate your efforts with social values that will appeal to the public and, to the degree possible, connect your group with valued and credible public persons.

You can create additional pressure toward changes if you can show that other groups with high credibility support the changes you propose. To gain this cooperation you must be able to show related groups how they will benefit from the changes you propose and you will have to show a willingness to support these groups in their own efforts.

The specific actions you take to achieve your objective depend on your issue. The actions you decide on should be part of an overall plan. Advocacy planning is discussed in chapter six. The planning form included in that chapter can be used, perhaps with modifications, to plan your systems effort. In developing your plan, bear in mind that you are not likely to win any real changes in a single negotiation session. You should view the first session as a success if you are able to define the problem and establish your knowledge of the issues and commitment to a long-term effort.

It is not a good idea to accept an initial solution proposed by the other party too quickly. Even if it looks good at face value, it may be designed to pacify more than to create any real change. If you find your group in this situation, take time to study the offer since you do not have to commit to a solution until you are ready. On the other hand, no proposed solution carries a guarantee of success. In many situations, the wisest course is to agree to a proposed solution on a trial bases, being sure to establish criteria which will be used to assess success and a time frame for reviewing the success of the proposed solution.

A systems advocacy effort is a demanding, challenging and exciting undertaking. It demands care, thought and commitment but the payoffs are well worth the effort. As a novice systems advocate you need not feel alone. Consultation and technical assistance are available from established advocacy groups and agencies such as Michigan Protection and Advocacy Service.

Michigan Protection and Advocacy Service has a Systems Advocacy Unit. The unit identifies systems issues which have an impact on persons with disabilities, develops strategies for changes and works with other agencies and individuals to bring about changes in laws, policy and systems practice designed to benefit persons with disabilities.

Appendix A

OVERVIEW OF RIGHTS OF CITIZENS WHO HAVE HANDICAPS

All citizens have rights guaranteed by state and federal constitutions and laws. Often people who have handicaps are discriminated against and denied basic rights. Therefore, special federal and state laws have been passed to protect rights of people who have handicaps. These laws are described below, along with a few other laws the advocate should know about.

FEDERAL LAWS

Developmental Disabilities Assistance and Bill of Rights Act

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) mandates the establishment of a state protection and advocacy service and guarantees these rights of individuals with developmental disabilities.

1. The right to treatment, services and habilitation that are designed to maximize the developmental potential of the individual.

2. The right to receive treatment, services and habilitation in a setting that is least restrictive of a person's rights and personal liberty.

3. If the individual resides in a publicly funded institution or other residential setting, that institution or facility must:

   a. provide nourishing, well-balanced diets;

   b. provide appropriate and sufficient medical and dental services;

   c. refrain from using physical restraints unless absolutely necessary and never as a punishment or substitution for an appropriate habilitation program;

d. refrain from using chemical restraints (medications) excessively or as punishment or as a substitute for habilitation programs;

   e. comply with adequate fire and safety standards.

4. In addition, any program receiving money under the DD Act must have an habilitation plan for every person in the program. The plan must be developed with input from the person who is disabled and/or the parent or guardian. The plan must be in writing and reviewed at least annually. (See 42 USC 6000 _et_ _seq_. & 45 CFR 1386.1 _et_ _seq_.)

Section 504

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against individuals with handicaps in employment and all aspects of service delivery and program access. It applies to any agency or business receiving federal money. Rights under Section 504 include:

1. Freedom from discrimination in all aspects of employment, including, but not limited to: recruitment, interviewing, hiring, promotion, employment benefits and conditions of employment, and

2. Freedom from discrimination in using any program or service provided by an agency receiving federal funds.

Section 504 requires program accessibility as well as the provision of reasonable accommodations needed to allow an individual to participate in programs provided by agencies receiving federal funds. It also requires employers to provide reasonable accommodations needed by a handicapped employee to do his/her job. (See 29 USC 794, 34 CFR 104.1 *et seq.* (Education), 45 CFR 84 *et seq.* (Health and Human Services).

Education for All Handicapped Act

The Education for All Handicapped Act provides every handicapped child between 3 and 21 years of age the right to a free appropriate public education. It includes the following rights.

1. An appropriate education at public expense.

2. A program that is individualized to meet the needs of the student; this is described in the student's written individualized education plan (IEP). The program is developed by a committee which includes the parent(s) and the student, if 18 years of age or otherwise appropriate.

3. The education is to be provided in the least restrictive environment.

4. Protection of the rights of the student and parents or guardians to due process, including the right to notification of changes in programs and/or location, the means of filing a complaint, and the way to request a hearing if in disagreement with the resulting IEP. (See 20 USC 1400 et seq. and 34 CFR 300.1 et seq.)

The Family Educational Rights and Privacy Act (FERPA)

The Family Educational Rights and Privacy Act (FERPA) gives parents the right to see the educational records of their minor children. Students 18 years old or older have the right to see their own educational records. This law also guarantees the following.

1. The right to request that the school correct any inaccurate information in the records and to have a hearing if the school refuses.

2. The right to confidentiality of records. Records may not be released to outside parties without written permission (See 20 USC 1232 g and 34 CFR 99.1 et seq.)

STATE LAWS

Mandatory Special Education Act

The Michigan Mandatory Special Education Act parallels the federal special education law in many ways. It extends the age limit of handicapped persons eligible for special education to birth through 26 years of age and specifies the ways special education services must be provided in Michigan. One of the most important points about the Michigan Mandatory Special Education Act is that it requires that the student's educational plan be designed to help the student achieve his/her maximum potential. (See MCLA 380.1701 *et seq.* and 1980 AACS 340.1701 *et seq.* and 1982 AACS 340.1701 *et seq.*)

Michigan Handicappers' Civil Rights Act

The Michigan Handicappers' Civil Rights Act is the Michigan law which prohibits discrimination based on handicaps. It says: "The opportunity to obtain employment, housing and other real estate and full and equal utilization of public accommodations, public services, and educational facilities without discrimination because of a handicap is guaranteed by this act and is a civil right." MCLA 37.1102(1). This law also requires the provision of reasonable accommodations. (See MCLA 37.1101 *et seq.*)

Michigan Mental Health Code

Michigan's Mental Health Code defines the manner in which services must be provided to people who have mental illness or developmental disabilities. Of particular importance are chapters 6 and 7. Chapter 6 is the section of law dealing with guardianship for people with developmental disabilities. It provides for different degrees of guardianship and states that guardianship should only be used to the degree necessary to protect the welfare of the developmentally disabled individual. Chapter 7 of Michigan's Mental Health Code describes the rights afforded to all persons receiving services from a public mental health agency in Michigan or from any agency under contract with a public mental health agency to provide services. Those rights are enumerated in the pamphlet entitled "Your Rights as a Resident of a State Center or Community Facility for the Developmentally Disabled," available from the Michigan Department of Mental Health. (See MCLA 330.1001 et seq.)

The Deaf Person's Interpreter Act

The Deaf Person's Interpreter Act guarantees the right to a qualified interpreter for a deaf person if arrested, if taking part in a court proceeding or if taking part in an administrative appeal or complaint regarding a government action. The interpreter fees must be paid by the unit of government with authority over the proceeding. (See MCLA 393.501 et seq.)

The Whistleblower's Act

The Whistleblower's Act protects employees who report a violation of local, state or federal law. It prohibits the employer from threatening, discriminating against or firing the employee under penalty of law. (See MCLA 15.361 et seq.)

Michigan Child Protection Law

The Michigan Child Protection Law requires professionals and paraprofessionals to report suspected cases of child abuse or neglect to the Department of Social Services under penalty of law. This law also describes the authority and responsibility of the Department of Social Services to investigate allegations and to take action to protect the child if the investigation shows a situation of abuse or neglect exists. (See MCLA 722.621 *et seq.*)

Social Welfare Act -- Protection of Vulnerable Adults from Abuse and Neglect

The Social Welfare Act requires professionals and paraprofessionals to report suspected cases of abuse or neglect of vulnerable adults to the Department of Social Services under penalty of law. A vulnerable adult is a person who is unable to protect him or herself from abuse or neglect because of a physical or mental impairment or old age. The act also describes the responsibility of the Department of Social Services to investigate reports and provide protection to the endangered adult, when needed. (See MCLA 400.11 *et seq.*)

Freedom of Information Act

The Freedom of Information Act requires public bodies to allow citizens to look at or copy public records. A public body is a unit of government or any entity which is created by state or local authority or which is primarily funded through state or local authority. A public record is any writing prepared, owned or used by a public body in carrying out its official function. There are some types of records which are exempt from disclosure, like personnel information, information that would interfere with law enforcement and academic records of students. A request to look at public records must be specific enough for the responsible authority to locate the record. (See MCLA 15.243 *et seq.*)

The Open Meetings Act

The Open Meetings Act requires public bodies to conduct almost all business at open meetings. The act also requires public bodies to post notices describing the date, time and location of their regular meetings. Public bodies include: the Michigan Legislature, the legislative or governing bodies of all counties, cities, villages, townships and charter townships. The law also applies to local intermediate and state boards of education, governing boards of all post-secondary educational institutions and special boards and commissions. (See MCLA 15.261 *et seq*.)

Note: This overview does not describe laws which focus primarily on financial benefits available to persons with handicaps or to the general population, such as Michigan's Family Support Subsidy Act or the federal Social Security Act.

APPENDIX B

UNDERSTANDING CITATIONS

A legal citation is a set of letters and numbers that describes how to locate a statute, regulation or rule. Below is a brief explanation of the conventions used in citing federal and state statutes, rules and regulations.

FEDERAL STATUTES

All federal statutes are called public laws, abbreviated as PL. Statutes are first introduced into Congress as bills. The first number of the public law identifies the Congress which enacted the bill. The second number identifies the order in which the bill was enacted. For instance:

Public Law ↖ P.L. 94-142 ↗ 142nd bill enacted
↓
94th Congress

P.L. 94-142 is the Education For All Handicapped Act. It is the federal special education law which guarantees a free, appropriate public education to persons with handicaps. It is found with other federal statutes in the United States Code (USC). The correct legal citation for P.L. 94-142 is 20 USC 1401 *et seq*. *Et seq* means "and subsequent sections." P.L. 94-142 is in Title 20, the education title. 1401 is the first section of P.L. 94-142.

Title 20 ↖

Section 1401 and
subsequent sections ↗

20 USC 1401 *et*. *seq*.

↓
United States Code

FEDERAL REGULATIONS

Federal regulations are compiled in the Code of Federal Regulations (CFR). P.L. 94-142 is found in Title 34 of the CFR. P.L. 94-142 regulations begin at Section 301.1 *et seq*. Recent changes in federal regulations are reported daily in the Federal Register; these regulations are abbreviated with FR in the citation.

Title 34

Section Where P.L. 94-142
regulations begin

↖ 34 CFR 301.1 ↗

↓

Code of Federal Regulations

STATE STATUTES

In Michigan, when a bill is enacted it is called a public act (PA), not a public law. Public acts are cited as follows:

Year bill was enacted

451st bill enacted

↖ 1976 PA 451 ↗

↓

Public Act

1976 PA 451 is the Michigan Mandatory Special Education Act. It guarantees a free appropriate education to persons who have a handicap. Just as public laws are compiled in the United States Code, Michigan public acts are compiled in a set of reference books called the Michigan Compiled Laws. Michigan Compiled Laws is abbreviated as MCL. Section 380 of MCL contains most of the education statutes in Michigan. The part of education law which deals with special education begins at subsection 1701. The full legal citation for PA 451 is MCL 380.1701 _et_ _seq_.

Michigan Compiled Laws ↖

Subsection where PA 451 is found ↗

MCL 380.1701 _et_. _seq_.

↓

Section cite for School Code of 1976

STATE REGULATIONS

The regulations that implement PA 451, the Michigan Mandatory Special Education Act, are called the Michigan Special Education Code. Even though these rules are called a "code", they should not be confused with the actual statute. They are rules.

The citation for the Michigan Special Education Code is 1980 AACS 340.1701 _et_ _seq_. AACS is the Annual Administrative Code Supplement. 1980 is the date of the supplement containing rules 340.1701 _et_ _seq_. Some of these rules have been amended since 1980. You should check later supplements for these changes.

Date of supplement

Location of PA 451 regulations

1980 AACS 340.1701

Annual Administrative Code Supplement

You may see state rules cited by the complete number, (R 340.1732) or simply by the last two digits (Rule 32).

Government Agencies and Departments in Michigan

1. **Michigan Department of Civil Rights**

   The Michigan Civil Rights Commission and the Michigan Department of Civil Rights are responsible for ensuring the civil rights of Michigan residents guaranteed by the state Constitution and statutes. Complaints regarding discrimination under the Michigan Handicappers' Civil Rights Act should be filed with the department. The department has several regional offices in the state. Staff will investigate the complaint, attempt to negotiate a resolution, and if conciliation fails, conduct a hearing and issue orders to remedy substantiated complaints. Michigan Department of Civil Rights, Leonard Plaza-Main Level, 309 N. Washington Square, Lansing, MI 48913 (517) 373-3590

2. **Michigan Department of Corrections**

   The prison inmate population includes individuals with handicaps. The Office of the Ombudsman for Legislative Correction is charged with the protection of inmate rights. This office is separate from the department and reports directly to the Legislature. Contact: Legislative Corrections Ombudsman, 4th Floor Farnum Building, Lansing, MI 48913 (517) 373-8573.

3. **Michigan Department of Education**

The State Board of Education (SBE), is a body of elected officials which determines policy for education in Michigan. Their meetings are public. Michigan Department of Education, P.O. Box 30008, Lansing, MI 48909 (517) 373-3324.

A. Special Education Services (SES) is the state agency responsible for ensuring that local educational agencies operate special education programs in compliance with federal and state law. This includes: monitoring, technical assistance, policy development and grants administration. Special Education Services, Michigan Department of Education, P.O. Box 30008, Ottawa Street Office Building, South Tower, Second Floor, Lansing, MI 48909 (517) 373-0923.

1. SES regional planners play key roles in providing technical assistance to local and intermediate districts and in mediating of some types of disputes. There are five regional planners.

2. The Special Education Advisory Committee (SEAC) is an appointed advisory body charged with providing public input to special education.

3. Each county has an intermediate school district (ISD) which is responsible for developing a special education plan for the county and for overseeing special

education provided by local schools in the county. An ISD may also provide some special education programs and services. See your local telephone directory index, county services - education.

4. Each ISD has a parent advisory committee (PAC). The PAC is an appointed parent advisory group responsible for providing input on the ISD's special education plan. Call your ISD for contact information.

B. Michigan Rehabilitation Services (MRS) operates the vocational rehabilitation program for all disabled individuals except those who are blind. The program is administered in Lansing and services are provided through a network of local offices. Michigan Rehabilitation Services, 608 W. Allegan, Ottawa Street Office Building, South Tower, Fourth Floor, Lansing, MI 48909 (517) 373-3390.

The Client Assistance Program (CAP) is an ombudsman service for MRS clients. You can call this program for help with problems regarding vocational rehabilitation services. Client Assistance Program, Michigan Department of Education, P.O. Box 30008, Lansing, MI 48909 1-800-292-5896.

C. Disability Determination Services (DDS). A large unit within the Department of Education which is under contract with the federal government to evaluate eligibility for Social Security disability benefits. This unit also conducts continuing disability investigations. Disability Determination Service, Michigan Department of Education, P.O. Box 30011, Lansing, MI 48909 (517) 373-7830.

D. Vocational Technical Education Services administers the vocational education program. Federal legislation funding vocational programs requires that a certain portion of the funds be used to provide reasonable accommodations to handicappers. Ottawa Street Office Building, South Tower, Second Floor, Lansing, MI 48909 (517) 373-3373.

E. Adult and Extended Learning oversees Adult Basic Education (ABE) and high school completion programs operated by local education agencies (LEA). Many LEAs provide ABE and high school completion programs to persons with handicaps. Ottawa

Street Building, South Tower, Second Floor, Lansing, MI 48909 (517) 373-8425.

4. **Michigan Department of Labor**

The Michigan Department of Labor administers some programs important to persons with handicaps.

A. The Michigan Commission for the Blind provides vocational rehabilitation services to individuals who are blind. This agency is the counterpart to the Department of Education/Michigan Rehabilitation Services. Leonard Plaza, 309 N. Washington, Box 30015, Lansing, MI 48909 (517) 373-2062.

B. The Michigan Commission on Handicapper Concerns provides legislative and systems level advocacy and technical assistance on behalf of handicappers. Leonard Plaza, 309 N. Washington, Box 30015, Lansing, MI 48909 (517) 373-8397.

C. The Division for the Deaf and Deafened provides legislative and systems level advocacy and technical assistance on behalf of deaf individuals. Leonard Plaza, 309 N. Washington, Box 30015, Lansing, MI 48909 (517) 373-0378.

5. Michigan Department of Mental Health

The Department of Mental Health (DMH) is the state level department responsible for the provision of mental health services to mentally ill, emotionally ill and developmentally disabled individuals, Below is a brief description of key programs serving developmentally disabled individuals. Lewis Cass Building, 6th Floor, Lansing, MI 48926 (517) 373-3740.

A. Office of Recipient Rights (ORR). The ORR is an internal unit charged with receiving and investigating allegations of abuse, neglect and rights violations occurring in the developmental disabilities regional centers and institutions for mentally ill individuals. The ORR advisors are assigned to geographic areas with at least one advisor assigned to each developmental disabilities regional center. The Michigan Standards for Community Mental Health Services recommend but do not mandate a recipient rights program for each CMH. The department's ORR unit provides technical assistance to CMHs on rights protection issues. Lewis Cass Building, 6th Floor, Lansing, MI 48926 1-800-854-9090.

B. The Michigan Developmental Disabilities Council (MDDC). The MDDC is responsible for studying the state's systems of services available to developmentally disabled individuals, developing a state plan, advocating at a systems level for improved services, funding demonstration projects to develop new services and developing regional interagency coordinating committees. The DD Planning Council is made up of representatives of departments, agencies, and consumer representatives. It has a staff within the Department of Mental Health. Lewis Cass Building, 6th Floor, Lansing, MI 48926 (517) 373-0311.

1. Regional Interagency Coordinating Committee (RICC). Field staff of the Michigan Developmental Disabilities Council are charged with the responsibility of developing RICCs. A RICC is a regional multi-county counterpart of the state level Council. They are voluntary groups made up of representatives of local service providing agencies and consumers with a goal of providing better coordination of services. Contact the Michigan Developmental Disabilities Council for further information.

C. Community Mental Health Boards (CMH). A long range goal of DMH is to transfer responsibility for the provision of mental health services to county CMHs. The administrative structure of the Community Mental Health program is established by the Board of County Commissioners. Several adjoining counties may establish a joint CMH. The Community Mental Health Board is appointed by the Board(s) of County Commissioners and is responsible for the administration, planning, budgeting and monitoring of CMH services. Community Mental Health Boards may provide services directly or through contracts with providers. CMH services must include crisis intervention and case management. They may include: residential services, day programming, social and recreational programs, respite care, parent training, counseling and other related services. Consult the county government listing in your telephone directory under mental health.

D. There is a state Association of CMH Directors and Boards called the Michigan Association of Community Mental Health Boards and Directors. P.O. Box 10081, Lansing, MI 48901 (517) 373-6443.

E. Family Support Subsidy is a monthly direct cash subsidy to families with a child who is severely mentally impaired, severely multiply impaired or autistic to help offset the high cost of care in the home. This subsidy is administered by DMH through the local CMHs. Consult the county government listing in your telephone directory under mental health.

6. Michigan Department of Public Health

The Michigan Department of Public Health (DPH) is responsible for the provision of public health services. 3500 N. Logan, P.O. Box 30035, Lansing, MI 48909 (517) 373-1387. Two programs are of particular importance for handicapped individuals. They are:

A. Division of Services to Crippled Children. This program provides: family assessment, case management and financial assistance in meeting the medical needs of individuals under 21 years of age, with a qualifying disability, chronic disease or medical condition, when the family's income is not adequate to cover the projected cost of medical care. The program is administered through the county DPH.

B. SSI Disabled Children's Program. Disabled children may receive SSI benefits, if the child meets Social Security disability criteria, and if the family meets financial eligibility criteria. If the child is eligible, the Social Security Office will refer the family to the DPH-SSI Disabled Children's Program. This program is to develop an individualized service plan for the child, to refer the family to agencies for needed services, to coordinate the plan and to assist the family in understanding the child's disability.

7. **Michigan Department of Social Services**

The Michigan Department of Social Services (DSS) administers a broad range of financial assistance, medical assistance and social services programs. It is the designated state agency for the administration of Title XX services and programs. Almost all services are delivered through a system of county offices. For information on programs listed below contact the Department of Social Services Office serving your county. The telephone number may be listed in local telephone directories under Michigan, State of - Social Service, Department of.

A. The Office of Legislative and Citizen Inquiries (Lansing) investigates complaints from citizens, agencies, legislators and others. It may recommend corrective action through administrative channels. Office of Legislative and Citizen Inquiries, 300 S. Capitol Ave., Box 30037, Lansing, MI 48909.

B. Financial Assistance Programs.

1. Financial Assistance Programs provided by DSS include: General Assistance (GA) or welfare, Aid to Families with Dependent Children (AFDC), Food Stamps and Emergency Needs Program (ENP).

2. The DSS also operates a Supplemental Security Income advocacy program which assists denied Supplemental Security Income applicants in appealing the denial.

C. Medicaid/Medical Assistance Program. The DSS administers the Medicaid program. It also provides Medical Assistance (MA) benefits and county hospitalization for others who are financially eligible. The adoption subsidy for adoptive families of children with special medical needs is also administered through this department.

D. Office of Services for Children and Youth - Protective Services Division investigates suspected cases of abuse or neglect of minors. If substantiated, a plan of service is developed to ensure the safety of the minor. This division also provides foster care placement for minors, adoption services, delinquency services, an Indian child welfare program and interstate services for the return of certain runaways and adoptive placement in other states.

E. Adult and Family Services.

1. Adult Protective Services. This program investigates allegations of abuse, neglect or exploitation of vulnerable adults. If substantiated, a protective services plan is developed to ensure the health and safety of the adult at risk.

2. Home Help Services. This program provides payments for personal care assistance and chore services (housekeeping) when such services are needed to maintain the independence of the individual and when the individual is financially eligible.

3. Adult Community Placement. This program provides preparatory and follow-up services to adults who need placement in adult foster care, nursing care facilities or homes for the aged.

F. Employment Development Services. Recipients of DSS financial assistance are required to enroll in an employment development program unless exempt. Services may include: training, placement, day care, transportation and relocation assistance.

G. Licensing of Foster Homes and Group Homes. The DSS is responsible for licensing of foster homes for adults and children and of group homes. It has partial responsibility for licensing of nursing homes.

Federal Agencies

8. The Social Security Administration

The Social Security Administration (SSA) is a federal agency which administers two income maintenance programs for individuals with disabilities severe enough that they cannot do any substantial gainful activity (SGA). These are: Retirement, Survivors, Disability and Health Insurance (RSDHI or Title II) and Supplemental Security Income (SSI or Title XVI). These disability benefit levels are administered through a network of local offices. In Michigan the determination of eligibility based on disability factors is contracted out to the Michigan Department of Education. Financial eligibility and benefit levels are determined by the SSA. Applications, inquiries and appeals are directed to the local SSA office. To find the office nearest you, consult your telephone directory under United States Government - Social Security District Office.

9. United States Department of Justice

The United States Department of Justice has ultimate responsibility for the enforcement of Section 504. Section 504 prohibits discrimination based on handicap. The Justice Department must ensure that each department develops 504 regulations and provides a complaint investigation and hearing procedure. When it is not clear which department is responsible for investigation of a given complaint, complaints should be filed with:

United States Department of Justice
Civil Rights Division
Coordination and Review Section
Washington, DC 20530

(202) 724-2227 Voice
(202) 724-7678 TDD

Complaints regarding discrimination in elementary and secondary education in Michigan should be filed with:

Office for Civil Rights, Region V
Department of Education
Elementary and Secondary Education Division
55 Erieview Plaza, Room 222
Cleveland, OH

(216) 522-4970 Voice
(216(522-7022 TDD

Other complaints regarding education should be filed with:

Department of Education
Office for Civil Rights
330 S. Wacker Drive
Chicago, IL 60606

(312) 886-3456

APPENDIX D

WHEN YOU NEED HELP/INFORMATION

PROBLEM/NEED	AGENCY	ADDRESS	PHONE NUMBER
Mental retardation information, rights, support, legislation and advocacy.	Association for Retared Citizens/Michigan	313 S. Washington Sq. Suite 310 Lansing, MI 48933	(517) 487-5426
Information and training on special education.	Citizens Alliance to Uphold Special Education (C.A.U.S.E.)	313 S. Washington Sq. Suite 040 Lansing, MI 48933	(517) 484-4084 1-800-221-9105
Information on handicapping conditions, rights, services and advocacy.	Center of Independent Living (nine locations in Michigan).	Call Michigan Council of Independent Living Programs c/o Grand Rapids Center of Independent Living; 3375 South Division Street Grand Rapids, MI 49508	(616) 243-0846
Information on vocational rehabilitation services and advocacy to resolve problems with vocational rehabilitation services.	Client Assistance Program	Michigan Department of Education P.O. Box 30008 Lansing, MI 48909	1-800-292-5896
Information and advocate assistance regarding vocational rehabilitation services for persons who are blind.	Client Assistance Program-Commission for the Blind	309 N. Washington Sq. P.O. Box 30015 Lansing, MI 48909	1-800-292-4200
Information on deafness, services rights, referral for advocacy assistance.	Division for Deaf and Deafened	Department of Labor 309 N. Washington Sq. P.O. Box 30015 Lansing, MI 48909	(517) 373-0379 Voice/TDD

WHEN YOU NEED HELP/INFORMATION

PROBLEM/NEED	AGENCY	ADDRESS	PHONE NUMBER
Epilepsy information, services and referral to support groups.	Epilepsy Center of Michigan	3800 Woodward Avenue Seventh Floor Detroit, MI 48201	(313) 832-0500
Learning disability information and advocacy.	Michigan Association for Children and and Adults with Learning Disabilities (MACLD)	20777 Randall Farmington, MI 48024	(313) 471-0790
Emotional illness information and education problems.	Michigan Association for Emotionally Disturbed Children	23555 Northwestern Hwy Southfield, MI 48075	(313) 356-2566
Information on handicapping conditions, services, rights and systems advocacy.	Michigan Commission on Handicapper Concerns	Department of Labor 309 N. Washington Sq. P.O. Box 30015 Lansing, MI 48909	(517) 373-8397 Voice/TDD
Advocacy, denial of services, general information on developmental disabilities, training and audio-visuals.	Michigan Protection and Advocacy Service	109 W. Michigan Avenue Suite 900 Lansing, MI 48933	(517) 487-1755 1-800-292-5923 Voice/TDD
Autism information, support, rights, and advocacy.	Michigan Society for Autistic Citizens	300 N. Washington Sq. Suite 205 Lansing, MI 48933-1204	(517) 487-9260 1-800-223-MSAC

WHEN YOU NEED HELP/INFORMATION

PROBLEM/NEED	AGENCY	ADDRESS	PHONE NUMBER
Blindness information.	National Federation of the Blind-Michigan	3761 Roosevelt Dearborn, MI 48124	(313) 563-3900
Denial of right in Department of Mental Health Services	Office of Recipient Rights--Dept. of Mental Health	Contact: 6th floor Lewis Cass Building Lansing, MI 48926	1-800-854-9090 or call facility for referral to the ORR officer.
Spina Bifida information and support	Spina Bifida Association of Michigan	20600 Coolidge Road Big Rapids, MI 49307	(616) 796-1621

GLOSSARY

Accessibility: A characteristic of programs, services or facilities indicating the degree to which they are useable by persons who have handicaps. This involves the removal of architectural barriers like curbs and stairs but also includes installation of adaptive devices such as braille signs, TDD's, visual warning signals for persons who are deaf and so on.

ACT: A law passed by a legislature. Synonym for statute.

Administrative Appeal: To present a case to administrators of an agency for reconsideration of decisions made at a lower level. The appeal usually provides an opportunity for a due process hearing, including the rights: to present evidence and witnesses, to cross-examine witnesses and to an impartial decision.

Advocacy: Problem solving to protect rights and to improve the welfare and life conditions of another or of oneself.

Barrier Free Design: Architectural designs which eliminate the types of barriers and hindrances that deter persons with handicaps from having access to and free mobility in and around a building or structure.

Bill: A proposed statute, not yet law.

Client Assistance Program: A program authorized by the Rehabilitation Act of 1973, as amended, to provide information and advocate assistance to individuals seeking vocational rehabilitation services.

Constitutional Right: A right guaranteed by the United States Constitution or the constitution of the state in which a person resides. For example, the rights of due process and equal protection are specified in the Fourteenth Amendment to the United States Constitution. Constitutional rights are rarely self-explanatory. They are interpreted by courts in specific cases. A federal constitutional right supersedes federal or state law.

Community Placement: The provision of residential services to a person with a handicap in family-sized facilities located in residential neighborhoods.

Deinstitutionalization: The ongoing effort to move persons who live in institutions and need residential services because of a handicap to family-sized settings located in residential neighborhoods. This effort is based on a commitment to integration and the principle of normalization.

Defendant: The party against whom a lawsuit is filed.

Developmental Disabilities: The term "developmental disability" means a severe, chronic disability of a person which:

(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(B) is manifested before the person attains age 22;
(C) is likely to continue indefinitely;
(D) results in substantial functional limitations in three or more of the following areas of major life activities: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Due Process: A right guaranteed under the Fifth and Fourteenth Amendments to the U. S. Constitution. The concept of substantive due process refers to all citizens' fundamental rights to life, liberty and property. Procedural due process refers to the fairness of procedures involved in any action which deprives people of their rights. Recent court rulings and legislation apply due process requirements to educational and treatment decisions. Courts have interpreted the right of due process to require, at a minimum, that a person receive reasonable notice and the opportunity for a fair hearing prior to being deprived of legal rights.

Equal Protection: A right guaranteed by the Fourteenth Amendment of the U.S. Constitution stating that all citizens are entitled to equal protection under the law -- that is, to be free from discrimination in the exercise of rights except where the state demonstrates a rational basis or compelling interest for apparently unequal treatment.

Exhaustion of Administrative Remedies: The doctrine that a person must attempt to resolve issues administratively before filing a lawsuit. Judges may decide not to hear certain kinds of cases unless administrative remedies have been exhausted.

Family Support: Services designed to help families who have a child with a disability provide the care and nurture needed by a child within his/her natural family and to prevent placement out of the home. This may include counseling, training and respite care.

Habilitation: The provision of programs and services to assist a person with a developmental disability to develop skills and competencies and to maintain a routine of self care.

Independent Living: The philosophy that persons who have handicaps have the right to live as independently as possible and should be provided encouragement and services designed to assist them in achieving a maximum level of independence.

Individualized Education Program: (IEP) A component of Public Law 94-142 that requires a written plan of instruction for each child receiving special education services. It includes: a statement of the child's present levels of educational performance, annual goals, short-term objectives, specific services needed by the child, dates when these services will begin and be in effect, and related information. The program is developed by a team including parent involvement.

Informed Consent: Permission from an individual or a legally authorized representative. Informed consent requires that: (1) complete information is provided about the choice, alternatives, risks and benefits; (2) the choice is voluntary; (3) the individual has the capacity to acquire and use information in making a choice.

Jurisdiction: The authority of a court to hear and decide a suit.

Least Restrictive Alternative: The legal concept that the government must accomplish its purposes in a manner which least infringes upon the rights of its citizens. The concept of least restrictive alternative means that services for persons with disabilities must be provided under the least confining and most normalized and integrated circumstances consistent with their needs.

Mainstreaming: The concept of serving persons who have handicaps within the regular school program, with support personnel and services, rather than placing children in self-contained special classes. This practice relates to the concept of least restrictive environment.

Normalization: The principle that services should be planned and delivered in ways that create culturally valued identities for persons who receive services. This is achieved through the use of culturally valued mechanisms for delivering services. It is the belief that individuals with disabilities have a right to live as normal a life as possible and that services should facilitate the achievement of a normal appearance, routine and conditions of everyday life.

Ordinance: A local law; that is, a city, town or county law.

P.L. (Public Law): The designation of a federal law. The numbers following "P.L." refer respectively to the session of Congress during which the law was passed and the order in which the law was passed in that session. For example, P.L. 94-142 was the 142nd law passed during the 94th Congress.

P.L. 94-142: The federal Education for All Handicapped Act of 1975, P.L. 94-142, requires that all handicapped children receive a free appropriate public education under the least restrictive circumstances possible. This law also mandates due process guarantees, nondiscriminatory testing procedures, individualized education plans (IEPs) and other safeguards of the educational rights of persons with disabilities.

Protection and Advocacy System (P&A): A state system to protect and advocate for the rights of people with developmental disabilities, as provided for by The Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The DD Act requires states receiving federal DD money to establish a P&A system and provides for federal allotments to fund this system. Under the

DD Act, the P&A system must be independent of any agency which provides services to persons with developmental disabilities and must have the authority to pursue legal, administrative and other appropriate remedies.

Section 504: This refers to Section 504 of the Rehabilitation Act of 1973, as amended. Section 504 prohibits discrimination against any handicapped individual by any organization receiving federal funds. The law requires that federally funded programs and services must be accessible to persons with handicaps and that reasonable accommodations be provided to otherwise qualified persons.

Shall/May: The term "shall" in a law, regulation or court order is mandatory, while the term "may" is discretionary. The term "may" allows flexibility in a party's actions, including the flexibility not to act at all.

Special Education: Programs and services provided to persons who cannot benefit from a regular education because of a handicap. Federal and state statutes guarantee the right to a free appropriate public education in the least restrictive setting and set forth the procedures to be used in providing special education programs and services.

Statute: A law passed by a state or federal legislature. Synonym for act.

Vocational Rehabilitation: A federally funded program authorized by the Rehabilitation Act of 1973, as amended. The program provides vocational evaluation, counseling, training and placement to persons who are handicapped.

ADVOCACY NOTEBOOK

Discussion Notes

DATE:________________ TIME:____________________

Kind of Discussion (telephone, meeting, other):__________

Discussion with:

Name:

Title:

Agency:

Address:

Telephone:

Reason for discussion:________________________________

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Summary:____

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Agreements/Conclusions:______________________________

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Follow up needed:____________________________________

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SAMPLE PLANS

Advocacy Planning Guide

Date: ______________________

The problem is: ____

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The ideal solution is: ______________________________________

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An alternate acceptable solution is: ________________________

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Who has authority to make changes:

Name: ______________________________ Position: ______________

Agency: ____

Address: ______________________________

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Telephone: ______________________________

Notes on the chain of command: ______________________________

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INFORMATION I NEED TO SUPPORT MY VIEWS

Information I already have: ______________________________

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Information I still need to obtain: ______________________

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My Arguments: ____

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Arguments the other party: may make:	My Counter arguments:
1. ____________________	1. ____________________
____________________	____________________
____________________	____________________
____________________	____________________
____________________	____________________
2. ____________________	2. ____________________
____________________	____________________
____________________	____________________
____________________	____________________
____________________	____________________
3. ____________________	3. ____________________
____________________	____________________
____________________	____________________
____________________	____________________
____________________	____________________

My Plan: ______________________________

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If My Plan Doesn't Work: ______________________________

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Results: ______________________________

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Agreements Reached: ______________________________

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When: ______________________________

Responsible Person: ______________________________

Telephone number: ______________________________

Address: ______________________________

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